More than meets the eye: An exploration of secondary school experiences and support for children and young people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

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Abstract

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, chronic medical condition affecting up to 2% of secondary school students in the UK. Characterised by debilitating fatigue and significant impairments in physical and cognitive functioning, ME/CFS can significantly affect school functioning. Despite this, UK-based research centring children and young people's (CYP's) perspectives on their school experiences, particularly regarding support, remains limited.

This paper explores the secondary school experiences of CYP with ME/CFS, including experiences of support, to gather insights into how educational professionals can better support them. Retrospective semi-structured interviews conducted with six CYP were analysed using Reflexive Thematic Analysis. Findings are situated within an ecological context, acknowledging how education systems and societal attitudes influence experiences.

This research highlights that there is more than meets the eye within the school experiences of CYP with ME/CFS. Physical, academic, social and emotional challenges make school participation hard work, requiring flexible and tailored adaptations to promote equity and inclusion. Whilst physical challenges are typically well recognised and supported, CYP often feel their social and emotional needs are overlooked and unsupported. A pervasive sense of invisibility shapes both their school experiences and support. Systemic barriers, including stigma, rigid systems, competing priorities, and power imbalances, further hinder access to timely, person-centred support in school. Relationships and resilience are key in supporting CYP in navigating the demands of secondary school with ME/CFS.

This research amplifies the voices of CYP with lived experience of ME/CFS and highlights opportunities for more equitable, inclusive and holistic support. Findings informed adaptations to Carr's 'BASE' model of inclusion and the development of a toolkit for school staff, Educational Psychologists, and school systems supporting CYP with ME/CFS. These contributions aim to improve understanding, attitudes, and support structures, ultimately enhancing experiences for CYP with ME/CFS in secondary schools.

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Abbreviations

BASE: Belonging, Mattering and Relationships; Autonomy; Sense of Safety; Equity

BPS: British Psychological Society

CHCs: Chronic Health Conditions

CYP: Children and Young People

DfE: Department for Education

DHSC: Department of Health and Social Care

EHCP: Education, Health and Care Plan

EP: Educational Psychologist

GCSE: General Certificate of Secondary Education

GEM: Grid Elaboration Method

HSP: Holistic Support Plan

IHP: Individual Healthcare Plan

IPA: Interpretative Phenomenological Analysis

LA: Local Authority

ME/CFS: Myalgic Encephalomyelitis (or encephalopathy)/Chronic Fatigue Syndrome

NA: Narrative Analysis

NICE: National Institute for Health and Care Excellence

PEM: Post-Exertional Malaise

RQ: Research Question

RTA: Reflexive Thematic Analysis

SENCO: Special Educational Needs Co-ordinator

SDT: Self-Determination Theory

SEMH: Social, Emotional and Mental Health

UK: United Kingdom

1. Introduction

1.1 Chapter Overview

This chapter will describe Myalgic Encephalomyelitis (or encephalopathy)/Chronic Fatigue Syndrome (ME/CFS), its prevalence, and the importance of considering school experiences for affected children and young people (CYP). Relevant theoretical frameworks will be drawn upon to support understanding CYP's experiences with ME/CFS within context. The chapter will conclude by proposing the role of education professionals, including Educational Psychologists (EPs), in supporting CYP with ME/CFS and the researcher's motivations for researching this topic.

1.2 Overview of ME/CFS in Children and Young People

1.2.1 ME/CFS Definition and Symptoms

ME/CFS is a complex and chronic medical condition affecting multiple body systems (National Institute for Health and Care Excellence [NICE], 2021). Recognised as a neurological and post-viral fatigue syndrome by the World Health Organization (2022), it is characterised by debilitating fatigue, significant loss of physical and cognitive functioning, and post-exertional malaise (PEM), a worsening of symptoms after physical or mental exertion, disproportionate to the level of activity (Rowe et al., 2017). Additional symptoms include unrefreshing or disturbed sleep, cognitive difficulties or 'brain fog', chronic pain, nausea, digestive problems, and heightened sensitivity to sensory stimuli (NICE, 2021).

Symptom severity varies, with mildly affected CYP often attending school part-time, while severe cases may require wheelchair use or be house- or bed-bound, causing prolonged school absences (Rowe et al., 2017). ME/CFS profoundly impacts quality of life, affecting emotional wellbeing, social relationships, and education (Parslow et al., 2016). Whilst ME/CFS symptoms can be managed, there is currently no known cure (NICE, 2021). Estimates for recovery rates vary; sustained recovery is rare in adults, but more common in CYP (Cairns & Hotopf, 2005; Joyce et al., 1997). As such, ME/CFS often requires lifelong adaptation (NICE, 2021).

1.2.2 Prevalence of ME/CFS

Prevalence estimates for ME/CFS in the UK vary widely due to issues with accurate incidence recording. Whilst it has been suggested that the prevalence of ME/CFS in the UK is 0.448% (Ponting, 2018), many argue that the figure is significantly higher (Lim et al., 2020; ME Research, 2024). Among CYP in the UK, estimates indicate that up to 2% of secondary school-aged children may be affected (Collard & Murphy, 2019).

The onset of ME/CFS peaks during adolescence, between the ages of 10 and 19, and again in adulthood, between the ages of 30 and 39 (Bakken et al., 2014). Females are disproportionately affected, with adolescent girls three to four times more likely to be diagnosed with ME/CFS compared with boys (Nijhof et al., 2011). ME/CFS affects people from all socioeconomic classes and ethnic backgrounds to a similar extent. However, it is believed to be underdiagnosed in Global Majority[1] groups, older adults, and people living in areas of multiple deprivation (Nacul et al., 2011; Ponting & Samms, 2024).

1.3 Outcomes and Impact

CYP with ME/CFS face unique and pervasive challenges that significantly impact quality of life, with studies showing this is markedly lower compared with healthy peers and those with other chronic health conditions (CHCs) such as type 1 diabetes or asthma (Kennedy et al., 2010; Roma et al., 2019). These challenges include disruptions to physical functioning, social relationships, independence, and personal identity (Parslow et al., 2016). This is considered to contribute to disproportionately high rates of mental health difficulties, with an estimated one-third of adolescents attending a specialist ME/CFS service meeting diagnostic criteria for depression and more than a quarter for an anxiety disorder (Loades et al., 2018).

Educational outcomes are also significantly affected. CYP with ME/CFS experience higher rates of school absences and poorer academic outcomes (Crawley & Sterne, 2009; Knight et al., 2018). ME/CFS is a leading cause of long-term and unexplained school absences in the UK, with affected students attending school for a median of two days per week and severe cases often resulting in absence for one year (Crawley et al., 2011; Davies & Crawley, 2008; Rangel et al., 2000). Such extensive absence has wide-ranging implications, affecting not only

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[1] The term ‘Global Majority’ is used throughout this paper to refer to people who are Black, African, Brown, dual-heritage, indigenous to the Global South, and/or who have been racialised as ‘ethnic minorities’ in Western contexts (Campbell-Stephens, 2021). It aims to acknowledge that these groups represent the majority of the world’s population and seeks to reframe and decolonise Eurocentric language and perspectives.

academic achievement but also social and emotional development, long-term career prospects, and overall wellbeing (Barnett et al., 2023).

Despite the clear educational implications, current research primarily focuses on attendance statistics, with limited exploration of broader school experiences or strategies to improve them (Tollit et al., 2018). Bridging this research gap is therefore important to equip education professionals to understand the needs of CYP with ME/CFS and provide effective support to promote inclusion and positive outcomes.

1.4 Understanding CYP's ME/CFS Experiences within Context

To understand CYP's experiences with ME/CFS within context, Bronfenbrenner's ecological (and later bioecological) theory is drawn upon (Bronfenbrenner, 1979, 1995; Bronfenbrenner & Morris, 1998, 2006). This provides a valuable lens through which to consider the role of proximal processes[2] and interconnected environmental systems[3] in directly and indirectly shaping CYP's experiences, as depicted in Figure 1.

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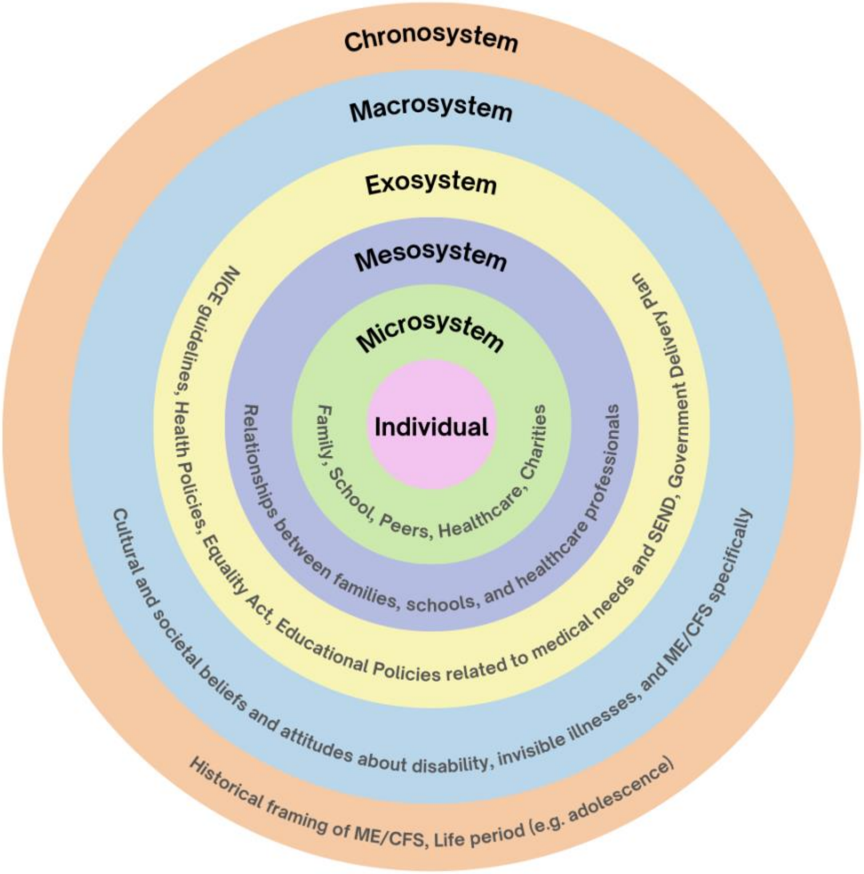
[2] Proximal processes are the dynamic, recurring, reciprocal interactions between individuals and their immediate environment, which play a central role in child development (Bronfenbrenner & Morris, 1998). These processes are a central mechanism through which other factors (such as personal characteristics, context, and time) exert their influence on CYP development.

[3] Bronfenbrenner (1979) described multiple levels of interconnected systems which form the context in which CYP develop: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem.

Figure 1

An Ecological Systems Perspective on ME/CFS in CYP



Note. Adapted from ecological systems theory by Bronfenbrenner (1979).

1.4.1 Individual

Individual factors, such as Bronfenbrenner and Morris' (2006) demand[4], resource[5], and force characteristics[6] (Figure 2), may influence how CYP with ME/CFS interact with their environment and proximal processes. Demand characteristics, such as gender and the invisible nature of symptoms, often shape

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[4] Demand characteristics are the observable attributes of an individual that can influence how others interact with them.

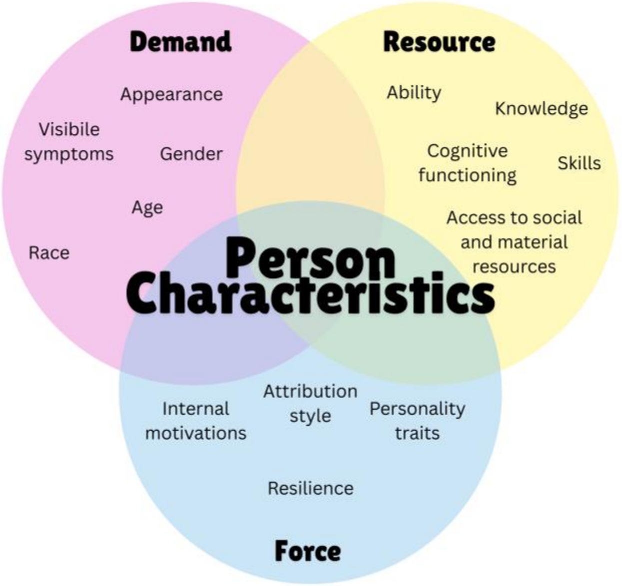
[5] Resource characteristics refer to an individual's mental, emotional, physical, and material resources, which affect their ability to engage in and benefit from proximal processes.

[6] Force characteristics are the internal qualities or dispositions that drive or inhibit an individual's engagement with their environment.

experiences of scepticism and support (Hunt et al., 2024; Wotherspoon, 2021). Resource limitations, like reduced physical and cognitive capacities and low levels of knowledge surrounding ME/CFS (Rowe et al., 2017), may hinder self-advocacy and access to support (Davies, 2021; Lewis, 2022). Although force characteristics such as personal agency, attribution style, and optimism can support coping, disruptions to functioning and identity may undermine these dispositions (Parslow et al., 2016).

Figure 2

Examples of Demand, Resource, and Force Characteristics Affecting CYP with ME/CFS



Note. Adapted from person characteristics described by Bronfenbrenner and Morris (2006).

Whilst attending to these various distinct characteristics, one must also consider the intersectionality of such individual factors (Crenshaw, 1989). Intersectionality highlights how overlapping aspects of identity, such as gender, race, class, and education, can create unique forms of oppression and shape experiences of stigma, dismissal, and access to diagnosis and appropriate care for people with ME/CFS (Bayliss et al., 2014; Hoffmann & Tarzian, 2001; Hunt et al., 2024). Burnham's (2012) Social Graces framework[7] supports the exploration of visible and invisible aspects of identity, which interact to shape experiences of inclusion, validation, and support; these should be considered when attempting to understand experiences.

1.4.2 Microsystem

The microsystem consists of the immediate environments CYP interact with, which are central in shaping experiences (Bronfenbrenner, 1979), such as families, school, peers, healthcare professionals, and charitable organisations. Proximal processes within these microsystems are crucial to consider, as research highlights that these relationships can act as sources of support or challenge (Parslow et al., 2016).

Families provide vital practical and emotional support, although dynamics are widely affected due to ME/CFS symptoms (Brigden et al., 2020; Parslow et al., 2016). Positive peer relationships are important for wellbeing, yet are often disrupted due to reduced social and school participation and misunderstanding about ME/CFS (Clery et al., 2022; Parslow et al., 2016). Interactions within schools and healthcare settings are also significant, as levels of understanding and legitimisation of ME/CFS

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[7] Burnham (2012) developed the Social Graces as a framework to explore aspects of social difference, power, and privilege. With input from Alison Roper-Hall (1998), he developed the mnemonic, which has now been extended to Social GGRRAAACCEEESSS (Burnham, 2018): gender, geography, race, religion, age, ability, appearance, class, culture, ethnicity, education, employment, sexuality, sexual orientation, and spirituality.

widely shape experiences, relationships, and support (Clery et al., 2022; Parslow et al., 2016). Despite statutory guidance promoting CYP's involvement in care planning (Department for Education [DfE], 2015; NICE, 2021), parents report a lack of empowerment and voice for CYP afforded by professionals (Webb et al., 2011). Consequently, CYP with ME/CFS face relational and systemic challenges within these microsystems that can perpetuate feelings of invalidation and hinder access to necessary support.

1.4.3 Mesosystem

Interactions and relationships between a CYP's microsystems shape experiences and development within the mesosystem. For CYP with ME/CFS, collaboration and communication across health, education, and family systems have been highlighted as necessary in facilitating support, with parents often acting as liaisons (Brigden et al., 2020). However, barriers such as delays in diagnosis, resource constraints, limited health-education communication, and scepticism surrounding the condition can hinder effective interactions, joint working, and consequent support (Brigden et al., 2020).

1.4.4 Exosystem

At the exosystem level, social structures, such as legislation, policies, and media, influence support systems for CYP with ME/CFS in health and education. For example, NICE (2021) guidelines provide recommendations for diagnosing and managing ME/CFS, including referral to specialist services. However, issues with access to these are widespread (Beasant et al., 2014), and access is inequitable across geographical, socioeconomic, and cultural dimensions (Collin et al., 2012; Linney, 2021).

Legislation such as the Equality Act 2010 mandates protection against discrimination and promotes equity and inclusion for those with disabilities, which may include ME/CFS. In education, the Children and Families Act 2014 and associated statutory guidance for pupils with medical conditions (DfE, 2015) emphasise the need to support full access to education whilst ensuring CYP remain healthy and safe, through measures like individual healthcare plans (IHPs). Despite this, use of IHPs is not routinely captured within the government's National Pupil Database and research has indicated low levels of compliance with medical conditions in education guidance (Health Conditions in Schools Alliance, 2022).

CYP with ME/CFS may have needs spanning any of the four areas[8] of Special Educational Needs and Disabilities (SEND). The SEND Code of Practice (DfE & Department of Health and Social Care [DHSC], 2015) emphasises the importance of person-centred approaches and coordinated support, where schools implement adaptations to meet needs, including through the provision of an Education, Health and Care Plan (EHCP) where necessary.

1.4.5 Macrosystem

The macrosystem encompasses the cultural, economic, political, and social ideologies and systems shaping CYP's environments and interactions. Consistent

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[8] The SEND Code of Practice (DfE & DHSC, 2015) identifies four broad areas of need, namely: communication and interaction; cognition and learning; social, emotional and mental health; and sensory and/or physical needs.

with a social model of disability (Oliver, 1983), these structures profoundly influence how disability is framed and experienced, particularly for CYP with CHCs like ME/CFS[9]. As an invisible condition, ME/CFS is often stigmatised and delegitimised due to the lack of visible symptoms, diagnostic markers, and treatments (Anderson et al., 2012). These societal attitudes adversely affect clinical, educational, and social interactions, healthcare access, and quality of life (Earnshaw & Quinn, 2012; Larun & Malterud, 2007).

In the UK, welfare reforms have further politicised ME/CFS, with the biopsychosocial model[10] (Engel, 1977, 1997) applied to neoliberal sociopolitical agendas (Hunt, 2024). This variant of the model downplays biological factors and unduly psychologises ME/CFS, exacerbating the physical, psychosocial, and economic burden of ME/CFS (Geraghty & Blease, 2019; Hunt, 2024). Dominant narratives and discourses, such as this, shape the construction of meaning and experiences (Bruner, 1990), reinforcing stigma and disability. This highlights the importance of challenging dominant narratives and promoting alternative stories to foster understanding and inclusion for CYP with ME/CFS.

Epistemic injustice[11] further exacerbates challenges, contributing to delayed diagnosis, inappropriate treatments, and psychological harm for individuals with ME/CFS (Blease et al., 2017; Geraghty & Blease, 2019; Hunt et al., 2024). This

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[9] Given the limited research on ME/CFS, this paper uses the term ‘CHCs like ME/CFS’ to facilitate comparison with other CHCs that are similarly associated with stigma and misunderstanding, and to encourage a broad lens for interpreting implications.

[10] The biopsychosocial model (Engel, 1977, 1997) acknowledges psychological and social factors alongside biology in health and illness.

[11] Epistemic injustice is a form of injustice against someone’s capacity as a knower (their ability to know, understand or share knowledge) (Fricker, 2007).

arises from prejudices discrediting the knowledge of individuals with ME/CFS and cultural frameworks disregarding lived experiences, perpetuated by systemic power dynamics (Fricker, 2007). Systemic barriers disproportionately affect Global Majority groups' access to appropriate ME/CFS support, increasing vulnerability to stigma and healthcare inequities (Bayliss et al., 2014; Hunt et al., 2024). To address social inequalities and promote equity and inclusion, amplification of the voices of those with lived experiences, particularly considering diverse experiences, is necessary.

1.4.6 Chronosystem

Temporal dimensions shape interactions and experiences for CYP with ME/CFS within the chronosystem (Bronfenbrenner & Morris, 2006). CYP’s developmental stage is critical as adolescence is a crucial period for identity formation, independence, autonomy, and establishing social and emotional connections (Bailey, 2006). Increased dependence on caregivers caused by ME/CFS can disrupt key tasks during this stage, undermining feelings of competence and impacting psychosocial wellbeing and development (Sansom-Daly et al., 2011; van Middendorp et al., 2001).

Historically, ME/CFS was framed as psychosomatic; this view contributed to stigma, disbelief, and inadequate support (Űstűnkaya & Machin, 2021). A pivotal event in time for ME/CFS was the publication of the PACE trial, a UK government-funded psychological study that endorsed graded exercise therapy and cognitive behavioural therapy as effective treatments for ME/CFS (White et al., 2011). This trial faced widespread criticism for significant methodological flaws and insufficient evidence to substantiate its claims (Wilshire et al., 2018). Furthermore, many patients reported harm associated with graded exercise therapy (Űstűnkaya & Machin, 2021). Updated NICE guidelines addressing these issues followed; however, persistent misinformation and mistreatment continue to shape significant gaps in research, public attitudes, and systemic responses. Within the UK, this has led to the publication of a cross-government interim ME/CFS delivery plan (DHSC et al., 2024) to improve understanding, experiences and support for CYP with ME/CFS. Whilst the government had planned to publish a final delivery plan by the end of March 2025, this has not yet happened at the time of writing.

The Covid-19 pandemic has shaped the current discourse by heightening attention to ME/CFS due to parallels with Long Covid, spurring increased awareness, research, and funding (Komaroff & Lipkin, 2023). Remote learning advancements during this period also improved experiences for CYP with ME/CFS (Similä, Nøst, et al., 2021). However, challenges within the current economy, such as austerity and the cost-of-living crisis, have increased financial pressures on schools and reduced access to resources for supporting CYP (Lucas & Julius, 2024). It has been argued that people with disabilities and CHCs like ME/CFS are often disproportionately affected by government cuts such as this (Hughes, 2015; Sakellariou & Rotarou, 2017), meaning that support for CYP with ME/CFS in schools at this current time may be a particular challenge due to systemic and temporal pressures.

1.5 The Role of Education Professionals

1.5.1 The Role of Schools

Application of a bioecological model highlights challenges that CYP with ME/CFS face at multiple levels within their systems, affected by the interplay of proximal processes, personal factors, context, and time. Whilst school is highly valued by CYP with ME/CFS, issues with school functioning and access to appropriate support are widespread (Knight et al., 2018; Parslow et al., 2020).

Schools have a crucial role in supporting CYP with ME/CFS in a holistic manner. The SEND Code of Practice (DfE & DHSC, 2015) and statutory guidance on supporting pupils with medical conditions (DfE, 2015) emphasise the duty of schools to promote equity and inclusion. Despite this, CYP and school staff alike indicate a lack of knowledge and understanding of ME/CFS within schools (Ali et al., 2019; Brigden et al., 2021) and CYP experience disparities in academic, social, and emotional outcomes (Knight et al., 2018; Parslow et al., 2016). Beyond learning, schools have a crucial role in supporting CYP's social and emotional development in order to prepare them for adult life (DfE & Gibb, 2015). As such, school experiences should be considered holistically, encompassing a breadth of academic, social, and emotional factors (Miller, 2014). Bridging the gap between legislation and practice is crucial for schools to promote inclusion and outcomes for CYP with CHCs like ME/CFS.

1.5.2 The EP Role

EPs are trained to work across multiple levels to listen to CYP’s views, consider their holistic needs, and help the systems supporting them to develop a shared understanding and appropriate response to various areas of need. EPs can complete assessments, such as those contributing to an EHCP needs assessment, consultation, training, intervention, and research to support this (Scottish Executive, 2002); therefore, they are well-placed to promote equity and inclusion for CYP with ME/CFS in schools (Brown & Cox, 1999; Jeffery, 2023). Despite this, scant published research has explored the EP role in supporting CYP with ME/CFS in school.

Recognising the important role of psychologists in supporting people to live with ME/CFS, the British Psychological Society (BPS) has been working with the DHSC on implementing NICE (2021) guidelines and is currently developing guidance for psychologists working with people with ME/CFS, including supporting CYP in education and the EP role (BPS et al., 2024; ME Association et al., 2024). Given the current evidence gap in this area, this research intends to gather insights to inform how EPs can improve experiences and support for CYP with ME/CFS in secondary schools.

1.6 Personal and Professional Interest in the Research Area

The researcher brings her own perspectives and experiences to this research, as an ‘insider-outsider’ researcher (Hellawell, 2006). Interest in this research area stemmed from the researcher’s own experience of living with ME/CFS during childhood, further sparked by professional observations of the limited awareness, understanding, and support for CYP with ME/CFS in educational settings today (see Figure 3).

Figure 3

Reflexive Diary Extract 1

Motivations for the Research

My interest in the school experiences of CYP with ME/CFS is shaped by both personal and professional motivations, grounded in a commitment to social justice and the amplification of voices often overlooked or silenced.

On a personal level, my connection to the area stems from my own experience of ME/CFS during childhood. I consider myself fortunate to have been able to recover, but this experience has given me a deep empathy for those living with ME/CFS. Now, as a healthy, able-bodied professional, I feel a responsibility to use my position to advocate for improve the experiences of CYP navigating ME/CFS in my role today.

Professionally, my interest was sparked by observations of the significant gaps in awareness, understanding, and support for CYP with ME/CFS in educational settings. Exploring the literature reinforced the need for further research to represent the voices of CYP with lived experiences and their needs within education.

Ultimately, my values of equity, inclusion, and listening to the quietest voices in our systems drive this work. By contributing to the field, I hope to foster greater understanding, challenge stigma, and advocate for educational practices that truly meet the needs of CYP with ME/CFS.

1.7 Nomenclature

Language is crucial in shaping perceptions, ideologies, and experiences (Galvin, 2003). Terminology holds power, not only to define, but also to affect lived experiences through its impacts on illness perception, self-identity, societal attitudes, and healthcare provision (Blease et al., 2017; Hunt et al., 2024; Wojcik et al., 2011). Within the ME/CFS community, debates around language reflect broader struggles for recognition and legitimacy, as terminology can validate or undermine the severity and complexity of the condition (Committee on the Diagnostic Criteria for ME/CFS et al., 2015; Petrison, 2015; Wotherspoon, 2021). Recognising these debates, the choice of ME/CFS in this study aims to align with current clinical guidelines (NICE, 2021), while remaining mindful of the terminology's limitations.

1.8 Chapter Summary

ME/CFS affects up to 2% of secondary school students in the UK (Collard & Murphy, 2019) and has pervasive impacts on all areas of functioning. School is an important outcome for this group (Parslow et al., 2020), yet attendance and school functioning are often reduced (Knight et al., 2018). This chapter adopted a bioecological approach to examine CYP’s experiences with ME/CFS in context, considering the dynamic interactions between process, person, context and time. To promote inclusivity and positive outcomes, developments in understanding school experiences and support needs of CYP with ME/CFS are essential. EPs offer an important role in amplifying the voices of CYP with lived experiences and improving knowledge, understanding and support within educational settings.

2. Literature Review

2.1 Chapter Overview

This chapter will summarise and critically appraise previous literature on school experiences of CYP with ME/CFS. It will detail the literature review purpose, question and review method. An overview and appraisal of the evidence base will then be described, followed by a thematic synthesis of the main findings. Finally, the contribution of the literature to the literature review question will be reviewed, and gaps identified. This will provide the context and justification for the current research.

2.2 Literature Review Purpose and Question

Literature reviews synthesise and critique evidence bases to give a contextualised understanding of what is currently known, assess evidence quality, and highlight gaps related to a particular research question (RQ; Braun & Clarke, 2021d; Siddaway et al., 2019).

The purpose of this literature review was to summarise the best available evidence related to the school experiences of CYP with ME/CFS, draw new insights from synthesising findings, and consider evidence gaps requiring further exploration. The literature review sought to explore the following question: What does the existing literature tell us about the school experiences of CYP who have ME/CFS?

2.3 Review Method

A systematic literature review approach was used to ensure replicability and transparency (Siddaway et al., 2019). Siddaway's (2019) guide was followed to apply a systematic method to identify, select, and critically appraise relevant research (Cochrane Collab., 2003). An RQ was identified, which informed a systematic search process using clear inclusion and exclusion criteria (Siddaway et al., 2019). This was a mixed studies review, which intended to combine quantitative and qualitative evidence to support breadth and depth in the understanding of the school experiences of CYP who have ME/CFS (Booth et al., 2022).

2.3.1 Search Strategy

A search was conducted in April 2024, via the EBSCOhost online research platform, of electronic databases of relevant disciplines, namely psychology, education, and health. Databases searched were APA PsycInfo, Education Source, ERIC, MEDLINE and CINAHL. This was supplemented by manual searches on Google Scholar, the British Library EThOS database, and through snowballing techniques, reviewing reference lists of relevant articles (Greenhalgh & Peacock, 2005).

The search was replicated in March 2025 to check for recently published literature. No additional literature that met the inclusion criteria was identified.

2.3.1.1 Search Terms. Search terms were created based on key concepts within the literature review question (Siddaway et al., 2019). This led to the identification of the following key words (see Table 1): ME/CFS, children and young people, and school. Search terms were then developed based upon these, considering synonyms, different spellings, and singular versus plural forms. Truncation symbols were used to search for variations of relevant search terms.

Table 1

Literature Review Search Terms

Subject Mapping Terms	Key Word Search Terms	Field
1. ME/CFS AND	"Myalgic encephalomyelitis" OR "Chronic fatigue syndrome"	Title
2. Children and young people AND	child* OR adolescen* OR pupil* OR student* OR paediatric* OR pediatric*	Abstract
3. School	School* OR education*	Abstract

Search terms and results were reviewed iteratively to ensure that the search captured all potentially relevant work. For example, the key word 'experience' was trialled but then removed and considered as part of the review inclusion criteria as it significantly reduced the literature retrieved. The Boolean operator "OR" was used to combine search terms related to each key word, and the operator "AND" was used to combine terms across the key words. Due to the focus of the literature review question on ME/CFS, these terms were searched within titles, whilst other key terms were searched within the abstract.

2.3.1.2 Limiters and Expanders. All searches were limited to papers published in the English language which had been peer reviewed. Peer review was considered important to ensure the inclusion of high-quality research, although limitations regarding publication bias were recognised. To mitigate the effects of publication bias, grey literature was searched for through Google Scholar and the British Library EThOS database.

The expander ‘apply equivalent subjects’ was included to expand the search to literature that may not have been captured using the chosen search terms.

2.3.2 Literature Selection

2.3.2.1 Inclusion and Exclusion Criteria. The criteria for inclusion and exclusion are detailed in Table 2. These were developed based on the literature review question before encountering the literature, in accordance with best practice (Siddaway et al., 2019).

Theses were included as the viva process was considered sufficient peer review. However, findings were synthesised separately from published journal articles due to differences in structure, length, depth, and review processes.

Table 2

Literature Review Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion	Rationale
Publication date	Published since 2012.	Published before 2012.	Significant developments have been made in the understanding of ME/CFS following publication of the PACE trial (White et al., 2011). This criterion should give wide enough scope to include relevant research whilst maintaining focus on up-to-date evidence.
Population	CYP with ME/CFS. This includes research with other populations	Not focusing on the target population of CYP with ME/CFS.	The literature review is focused specifically on experiences of CYP with ME/CFS.

Criteria	Inclusion	Exclusion	Rationale
	about CYP with ME/CFS.		
Subject of interest	Exploring school experiences of CYP with ME/CFS.	Topic not relevant to experiences of CYP with ME/CFS in relation to school.	To ensure the literature is appropriate to answer the question related to exploring school experiences of CYP with ME/CFS.
Peer reviewed	Peer reviewed, including doctoral theses subject to the viva process.	Not peer reviewed.	To ensure the inclusion of high-quality research, studies included within the review should have been subjected to peer review.
Methodology	Empirical research incorporating subjective components.	Not empirical research, for example a review, theoretical or opinion paper. Evaluation of an intervention. No subjective components.	To ensure that the review focused upon original research evidence which explored subjective experiences.
Location	Articles published internationally.	N/A	To support consideration of different experiences and approaches internationally, given limited research in the UK alone.
Language	Articles written in English.	Articles not written in English.	English is the only language spoken by the researcher.

2.3.2.2 Selection Process. The flow diagram in Appendix A outlines the selection process and results from the systematic review.

Initially, 120 articles were returned from database searches, which were reduced to 62 after duplicates were removed. References were exported to

EndNote, a citation manager, to collate results. These were evaluated against the inclusion and exclusion criteria. Titles and abstracts were scanned for relevance to the literature review question and inclusion criteria, leaving 14 articles. Full texts were then sifted for eligibility, leading to seven articles being excluded and seven articles included (see Appendix B for an overview of full texts assessed with rationale for inclusion and exclusion). The manual search identified nine additional records, six of which were included following the full text review. In total, 13 studies were included in the literature review (see Appendix C).

2.3.3 Organisation of the Literature Review

2.3.3.1 Critical Appraisal. Each paper included within the review was critically appraised using a tool to support assessment of study quality. This was considered important to assess the extent to which conclusions could be reliably drawn from the review findings.

The following tools were used as frameworks to support critique, selected based upon each study's adopted methodology:

- The Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP, 2018)
- The Mixed Methods Appraisal Tool (MMAT) Version 2018 (Hong et al., 2018)
- The Critical Appraisal of a Survey Tool (Center for Evidence-Based Management, 2014)

A critical appraisal of studies is presented in tabular format in Appendix D and is discussed within the literature overview and appraisal.

2.3.3.2 Synthesis. Since this was a mixed studies review, the synthesis aimed to combine and integrate quantitative and qualitative data.

Thematic synthesis was utilised for qualitative data to consider patterns and generate hypotheses regarding school experiences for CYP with ME/CFS (Booth et al., 2022). This method facilitated a rigorous and inductive approach to exploring common themes across studies. Studies were uploaded into NVivo, a software program, to inductively code and then translate into themes (see Appendix E) in an iterative process (Cruzes & Dyba, 2011; Houghton et al., 2017). Since the raw data of a qualitative systematic review consists of ideas or concepts, the results and discussion sections of qualitative studies were reviewed for synthesis (Noyes et al., 2018).

Narrative synthesis was used for quantitative data due to the heterogeneity in methodologies and outcomes amongst studies. This approach supports the integration of findings to tell a story of the literature (Booth et al., 2022), thus enabling a descriptive summary of findings and facilitating interpretation of quantitative data within the context of qualitative themes.

To integrate the qualitative and quantitative data within the synthesis, a thematic framework was first developed from qualitative studies. Quantitative data was then mapped onto the qualitative themes to explore how it supported, contrasted with, or extended the experiences reported in qualitative literature (Booth et al., 2022). This integrative approach enabled findings to be written up thematically, with each theme primarily grounded in the qualitative thematic synthesis and enriched by interwoven quantitative findings. This maintained the depth and richness of qualitative data whilst adding breadth and some triangulation through the quantitative data.

2.4 Literature Overview and Appraisal

2.4.1 Aims and Methodology

Studies included within the literature review had a range of aims. Several focused upon general experiences of ME/CFS in CYP (e.g. Parslow et al., 2020; Similä et al., 2020; Winger et al., 2014). Some explored experiences from a healthcare perspective, integrating aspects of schooling (e.g. Brigden et al., 2020; Parslow et al., 2017). Six studies focused exclusively on school experiences (Brigden et al., 2021; Clery et al., 2022; Davies, 2021; Knight et al., 2018; Lewis, 2022; Similä, Rø, et al., 2021).

To achieve these aims, studies predominantly adopted qualitative methodologies (10 of 13) to obtain rich, in-depth insights into experiences. Due to the smaller sample sizes and context-specific, highly subjective nature of qualitative research, transferability of findings in different contexts may be limited. Quantitative methodologies were included within one mixed-methods study (Ali et al., 2019) and two cross-sectional studies (Knight et al., 2018; Similä et al., 2020). This facilitated greater breadth of perspectives, although it often failed to capture depth and complexities related to experiences. The combination of qualitative and quantitative evidence was, therefore, a strength of the evidence base.

Two studies included within the review were doctoral theses conducted by Trainee EPs (Davies, 2021; Lewis, 2022). These differed in their structure, length, depth, and review processes, which may limit rigour, scrutiny and validation.

The two theses were the only studies included within the literature review that described researcher positionality and ontological and epistemological stances. A lack of transparency regarding researcher positionality within published journal articles may limit the credibility and trustworthiness of findings.

2.4.2 Participants and Sampling

CYP formed at least part of the participant group for 10 out of the 13 included studies. The three studies that did not include CYP as participants explored professional perspectives from school staff (Brigden et al., 2021; Similä, Rø, et al., 2021) and healthcare professionals (Parslow et al., 2017). Table 3 displays participant groups for the included studies.

Table 3

Participant Groups and Sample Sizes from Literature Review Studies

Study	Children and Young People	Parents	School Staff	Healthcare Professionals
Ali et al. (2019)	51	-	-	-
Brigden et al. (2020)	8	24	11	9
Brigden et al. (2021)	-	-	11	-
Clery et al. (2022)	15	16	-	10
Knight et al. (2018)	39 with ME/CFS, 28 healthy controls	-	-	-
Parslow et al. (2017)	-	-	-	15
Parslow et al. (2020)	21	22	-	-
Similä et al. (2020)	63	-	-	-
Similä, Nøst, et al. (2021)	18	-	-	-
Similä, Rø, et al. (2021)	-	-	12	-
Winger et al. (2014)	18	-	-	-
Davies (2021)[a]	2	-	-	-
Lewis (2022)[a]	3	-	-	-

[a] Doctoral thesis research study.

Most studies focused on the views of one participant group, however, a few considered multiple perspectives (Brigden et al., 2020; Clery et al., 2022; Parslow et al., 2020). The multi-perspective approach contributes to a nuanced understanding of multiple and interacting perspectives within CYP's systems (Larkin et al., 2019), so integration of these supports triangulation (Annan et al., 2013). However, this may have influenced the extent to which the voices of CYP were centred within findings.

In line with evidence on peaks in incidence of ME/CFS across the lifespan (Bakken et al., 2014), most research focused on adolescence, although two studies considered experiences at the primary school phase (Brigden et al., 2020; Brigden et al., 2021). Similarly, participants with ME/CFS were predominantly female, in line with gender prevalence rates (Nijhof et al., 2011). The voices of CYP with severe

ME/CFS appeared to be limited within research due to sample exclusion criteria (e.g. Clery et al., 2022), although Ali et al. (2019) specifically focused on this group in their research[12].

The majority of studies (8 of 13) were conducted within the UK, whilst four were conducted in Norway (Similä et al., 2020; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021; Winger et al., 2014), and one in Australia (Knight et al., 2018). When comparing findings between studies, the potential influence of different education and healthcare systems and societal attitudes on experiences must be considered. It is important to note that half of the UK-based studies recruited participants from one large paediatric specialist ME/CFS service within the South West of England (4 of 8). This may not be representative of other regions with different demographics and access to specialist support.

Most studies described recruitment strategies which were appropriate to address research aims, such as purposive and convenience sampling. Although some studies purposively sampled to ensure diversity in age, gender, and level of school attendance (e.g. Brigden et al., 2021; Parslow et al., 2020), just one study explicitly attempted to include participants from Global Majority groups (Clery et al., 2022). Participant characteristics related to aspects of identity, such as ethnicity, were rarely reported. Consequently, little is known about how experiences may differ according to various intersecting aspects of identity. Given suggestions that ME/CFS is under-identified within Global Majority groups, the absence of consideration of

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[12] Ali et al. (2019) used a self-report functional ability scale (Moss, 2005) to assess severity and inform eligibility for this study. The severity score threshold was raised within the second phase of research to recruit a further three participants, however, so the sample may have also captured some with moderate symptoms according to NICE (2021) guidelines.

ethnicity within research may neglect differences in experience associated with identity factors (Nacul et al., 2011).

The opt-in sampling approaches commonly used were ethically appropriate, given the impact of ME/CFS on energy impairment and capacity for participation. However, self-selection increases the risk of sampling bias, as individuals with particularly salient experiences or interest in the area may be more likely to participate. Findings may, therefore, not fully represent all experiences.

2.4.3 Methods of Data Collection and Analysis

2.4.3.1 Data Collection. Data collection methods were a relative strength of studies included within the review. Most studies utilised semi-structured interviews to facilitate in-depth exploration of experiences. Topic guides were typically based upon relevant evidence, professional expertise, and research aims. In some cases, these were developed in consultation with patient and public advisory groups to ensure sensitivity and comprehensive question design (Brigden et al., 2020; Brigden et al., 2021).

Some studies used creative data collection methods to capture participant experiences. Parslow et al. (2020) utilised a card-ranking exercise as an interactive, child-friendly technique to explore experiences whilst minimising interviewer effects. Additionally, Lewis (2022) utilised diaries as a participant-led data collection method to explore narratives. Creative approaches were useful to facilitate research engagement and minimise potential harms, given that energy impairment and cognitive difficulties are common symptoms of ME/CFS (Rowe et al., 2017).

Quantitative (Knight et al., 2018; Similä et al., 2020) and mixed-methods studies (Ali et al., 2019) utilised surveys. Validated measures were used to reliably measure key factors, such as fatigue and wellbeing[13].

A key limitation is that most studies were not primarily designed to collect data about school experiences, likely omitting key information related to this topic. For example, despite reporting specifically about school experiences, Clery et al. (2022) used secondary data from other studies which had not aimed to explore school experiences.

2.4.3.2 Data Analysis. The majority of qualitative data was analysed using thematic analysis (e.g. Brigden et al., 2020; Brigden et al., 2021; Clery et al., 2022; Parslow et al., 2017), which enabled exploration of common themes experienced by participants (Braun & Clarke, 2013). Other approaches included grounded theory (Similä, Nøst, et al., 2021) and phenomenological approaches (Similä, Rø, et al., 2021; Winger et al., 2014).

Both theses used analytical methods focused upon individual experiences, namely narrative analysis (NA; Lewis, 2022) and interpretative phenomenological analysis (IPA; Davies, 2021). These methods empowered the voices of those with lived experiences, although interpretations were inherently subjective and influenced

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[13] Common measures of fatigue included the Pediatric Quality of Life Inventory-Multidimensional Fatigue Scale self-report (Varni et al., 2001) and the Chalder fatigue scale (Cella & Chalder, 2010; Chalder et al., 1993). Various measures of wellbeing were used, including the Strengths and Difficulties Questionnaire (Goodman, 2001), the Short Mood and Feelings Questionnaire (Sharp et al., 2006), the PHQ-2 (Löwe et al., 2005) and the GAD-2 (Spitzer et al., 2006). School-specific measures included the Pediatric Quality of Life Inventory-Multidimensional School Functioning Scale (Varni et al., 2001) and the Psychological Sense of School Membership (Goodenow, 1993).

by the researcher. Furthermore, transferability is limited due to the highly individualised and context-specific nature of insights developed from these analytical approaches.

Many studies demonstrated rigour in data analysis. Analytical procedures were explicitly reported (Davies, 2021; Lewis, 2022; Winger et al., 2014), and some double-coded a subset of the data for trustworthiness (Brigden et al., 2021; Clery et al., 2022; Parslow et al., 2020; Parslow et al., 2017). Illustrative quotes supported themes (e.g. Clery et al., 2022), and member checking was used within one thesis (Lewis, 2022).

Quantitative data was analysed using descriptive statistics, correlational analysis, two-sided independent t-tests and multiple regression analyses (Ali et al., 2019; Knight et al., 2018; Similä et al., 2020). All studies assessed statistical significance, although only Knight et al. (2018) and Similä et al. (2020) gave confidence intervals for the main results. However, statistical models failed to include all potential confounding factors, such as socioeconomic status or family factors.

2.4.4 Reflexivity and Ethics

2.4.4.1 Reflexivity. A key limitation was the lack of attention to the researcher-participant relationship across the literature. Beyond clarifying that researchers were not part of the clinical team in some studies (e.g. Brigden et al., 2021; Parslow et al., 2020), few addressed researcher reflexivity or potential influence. This is significant given the high level of bias and misunderstanding surrounding ME/CFS (Hughes et al., 2023). Only the two theses explicitly considered reflexivity related to how researchers may have shaped the data to enhance transparency (Davies, 2021; Lewis, 2022).

2.4.4.2 Ethics. Ethical issues such as obtaining ethical approval, informed consent, confidentiality, and anonymity were explicitly addressed within studies. Furthermore, studies described ethically appropriate consent and assent procedures, including CYP, families, and professionals.

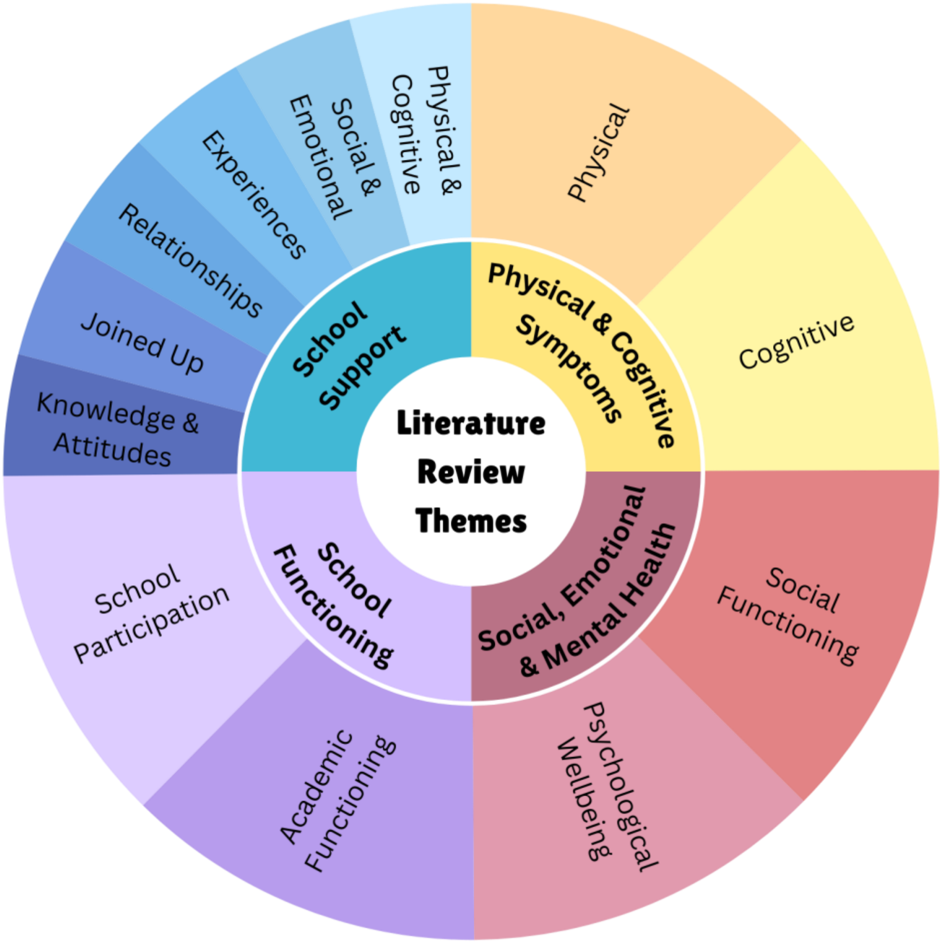
However, only two studies addressed minimising harms related explicitly to ME/CFS. Lewis (2022) offered reasonable adjustments to the recording of diaries to reduce the cognitive burden and Davies (2021) minimised potential harms by offering flexible timings, rest breaks and screen breaks.

2.5 Literature Review Themes

Given differences in the structure and methodology of theses compared with journal articles, these are presented separately at the end of the thematic synthesis, compared against themes highlighted within the main body. Themes identified within the literature review are displayed in Figure 4.

Figure 4

Themes Identified within the Literature Review



2.5.1 Physical and Cognitive Symptoms

2.5.1.1 Physical Symptoms. CYP with ME/CFS displayed visible, debilitating physical symptoms, recognised by parents, teachers, healthcare professionals and CYP themselves (Brigden et al., 2021; Parslow et al., 2020; Parslow et al., 2017). Symptoms varied between CYP and fluctuated over time (Ali et al., 2019).

Both quantitative and qualitative studies widely found chronic disabling levels of fatigue amongst CYP with ME/CFS, which impacted daily functioning, including school experiences (Ali et al., 2019; Brigden et al., 2021; Knight et al., 2018; Parslow et al., 2020). Quantitative analysis revealed that fatigue levels explained a substantial amount of the variation in school attendance, quality of life in school, school participation, and school connectedness in Australian CYP with ME/CFS (Knight et al., 2018).

Many CYP reported finding the demands of school tiring, leading to reduced attendance, needing to take additional rest breaks, and difficulties keeping up with schoolwork (Parslow et al., 2020). The more physical activities CYP pushed themselves to participate in, the more payback they typically experienced, leading to further reduced activity levels (Parslow et al., 2017; Similä, Nøst, et al., 2021).

2.5.1.2 Cognitive Symptoms. Cognitive functioning was also impacted, affecting CYP's ability to keep up with schoolwork (Parslow et al., 2017). Adolescents, parents, and school staff described difficulties such as brain fog, slower pace of work, and difficulties with processing, multi-tasking, memory, and attention (Brigden et al., 2021; Parslow et al., 2020).

As a result of physical and cognitive symptoms of ME/CFS, adolescents, parents, and teachers frequently described a ripple effect on academic, social, and emotional functioning (Brigden et al., 2021; Clery et al., 2022).

2.5.2 Social, Emotional, and Mental Health

2.5.2.1 Social Functioning. Adolescents with ME/CFS faced significant disruptions to their social lives (Parslow et al., 2020), with moderate to severe impacts on social functioning (Ali et al., 2019). Limited energy levels due to fatigue necessitated reduced levels of social and school participation, hindering CYP's ability to build or maintain friendships (Clery et al., 2022; Lewis, 2022; Similä, Nøst, et al., 2021; Winger et al., 2014). This led to experiences of social isolation, loneliness, and frustration (Brigden et al., 2021; Similä, Nøst, et al., 2021; Winger et al., 2014).

A lack of understanding and, in some cases, disbelief from peers regarding school absences and symptoms were commonly described by teachers, healthcare professionals, and CYP (Brigden et al., 2021; Clery et al., 2022). CYP often described difficult social interactions where they felt misunderstood, delegitimised, negatively labelled, or pitied by their peers (Clery et al., 2022; Winger et al., 2014).

A sense of loss related to social experiences and concerns about the longer-lasting impacts on social development and independence was highlighted by some CYP and healthcare professionals (Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021). Missed opportunities for social development during the key stage of adolescence raised worries about entering adult life (Parslow et al., 2017; Similä, Nøst, et al., 2021).

While UK research on school belonging is limited, international studies report lower school connectedness (Knight et al., 2018; Similä, Rø, et al., 2021) and feelings of invisibility within school (Winger et al., 2014). In the UK, primary school teachers acknowledged the importance of promoting inclusion and belonging for CYP with ME/CFS (Brigden et al., 2021). However, little research has explored factors supporting positive social experiences in education. A Norwegian study revealed variation in the degree to which time for social interaction, such as break times, was prioritised within educational plans (Similä, Nøst, et al., 2021). This has not yet been explored in the UK.

2.5.2.2 Psychological Wellbeing. Quantitative studies found that CYP with ME/CFS experienced greater levels of emotional symptoms compared with healthy controls (Knight et al., 2018). Almost one-third of CYP with severe ME/CFS, surveyed using validated measures, self-reported scores that were consistent with clinical depression (Ali et al., 2019).

Similarly, difficulties with psychological wellbeing were widely described by CYP in qualitative research. Low mood, frustration, hopelessness, worry, and anxiety were frequently described (Ali et al., 2019; Clery et al., 2022; Parslow et al., 2020; Similä, Nøst, et al., 2021). This was particularly due to the limitations that ME/CFS placed on CYP’s school and social participation (Ali et al., 2019; Parslow et al., 2020; Similä, Nøst, et al., 2021). Teachers, parents and healthcare professionals also described CYP losing confidence, becoming less outgoing, experiencing mood swings, low self-esteem, anxiety, and depression (Brigden et al., 2021; Parslow et al., 2020; Parslow et al., 2017; Similä, Rø, et al., 2021).

School experiences were often entwined with psychological wellbeing. CYP experienced stress and anxiety regarding school and social participation, catching up with classwork, academic achievements, and coping with symptoms in school and social situations (Clery et al., 2022; Parslow et al., 2020). This impacted some CYP’s academic self-concept and self-esteem and led to some reluctance towards attending school (Parslow et al., 2020). Some parents and healthcare professionals also felt that school, particularly exams and the return to school after prolonged absence, negatively impacted mental health and consequently exacerbated ME/CFS symptoms (Clery et al., 2022; Parslow et al., 2017). Conversely, positive experiences of support within school were associated with better levels of emotional and psychosocial functioning (Similä et al., 2020).

2.5.3 School Functioning

2.5.3.1 School Participation. School attendance was significantly impacted for CYP, despite being widely prioritised (Clery et al., 2022). In Australia, a survey revealed that CYP with ME/CFS had missed an average of 40% of the school term due to illness (Knight et al., 2018). Higher absence rates were observed among females, those with severe ME/CFS, and those accessing treatment (Ali et al., 2019; Similä et al., 2020).

The degree to which school participation was prioritised varied between participant groups and studies. In one multi-perspective study, CYP, parents and healthcare professionals agreed that returning to school was important for improving mood, educational opportunities, and social connectedness (Clery et al., 2022). However, in a card-ranking exercise, CYP ranked school more highly than their parents, who prioritised health outcomes (Parslow et al., 2020). Healthcare professionals were also more cautious, valuing reduced attendance to support functioning, while balancing this with acknowledgement of schools' importance for CYP's sense of normality and social contact (Parslow et al., 2017).

Home tuition and online learning offered alternative methods for engaging with education (Ali et al., 2019; Similä, Rø, et al., 2021). In Australia, other methods included a visiting teacher service, private tutoring, individual school tuition, and access to distance education (Knight et al., 2018). A Norwegian study revealed positive experiences of moving into a special educational setting for two CYP, despite initial difficulties adjusting to this change (Similä, Nøst, et al., 2021).

2.5.3.2 Academic Functioning. CYP, parents, and healthcare professionals frequently mentioned the impacts of cognitive impairments on academic abilities and keeping up with schoolwork (Clery et al., 2022; Parslow et al., 2020; Parslow et al., 2017).

Achievement testing amongst Australian CYP with ME/CFS indicated significantly lower academic performance compared with healthy controls (Knight et al., 2018). However, this study failed to control for confounding factors beyond age and estimated intelligence. In Norway, 76% of CYP surveyed had experienced delayed school progression due to not being able to complete all compulsory subjects at their level (Similä et al., 2020). This experience was negatively associated with physical, social, school, and psychosocial functioning (Similä et al., 2020). Despite this evidence, there is a paucity of published research in the UK, particularly qualitative research, exploring academic experiences in greater depth.

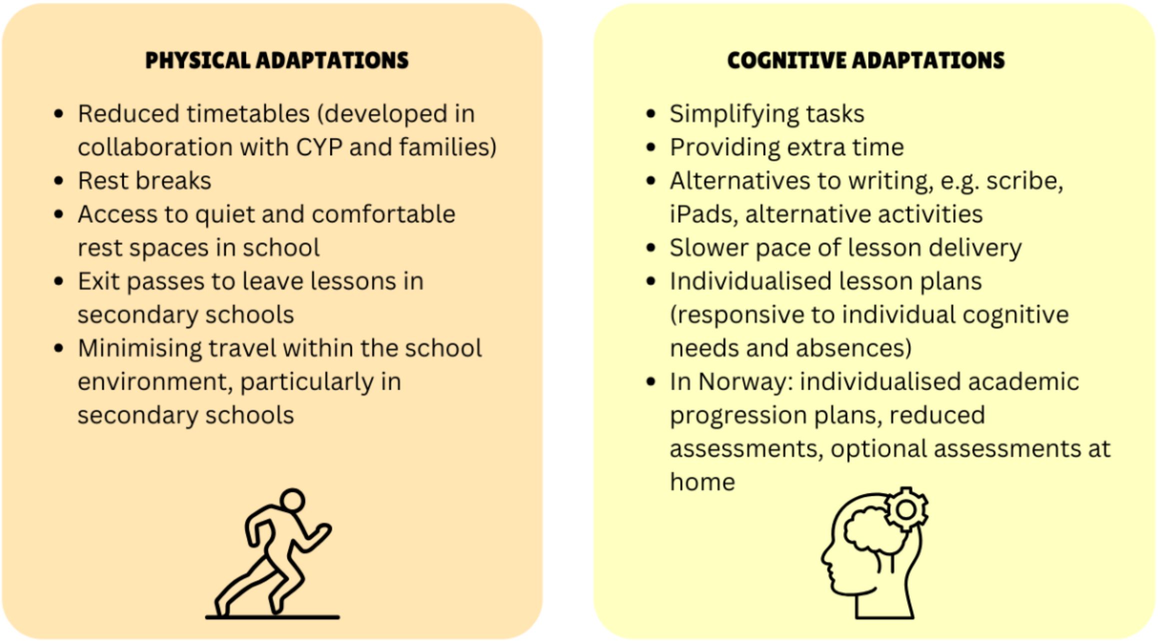
Challenging academic experiences impacted the academic self-concept and aspirations of, and for, many CYP (Clery et al., 2022; Parslow et al., 2017). Concerns about long-term impacts on educational and career opportunities were frequently shared by secondary school-aged CYP and their parents (Clery et al., 2022), particularly amongst 14- to 15-year-olds regarding General Certificates of Secondary Education (GCSEs) (Parslow et al., 2020).

2.5.4 School Support

2.5.4.1 Support for Physical and Cognitive Needs. Given that physical and cognitive symptoms associated with ME/CFS were an obstacle to participation (Winger et al., 2014), widespread adaptations to support school functioning were required, with common examples noted in Figure 5. Teachers in the UK widely described physical adaptations, acknowledging their key role in regulating the activity levels of children with ME/CFS to avoid overexertion (Brigden et al., 2020; Brigden et al., 2021).

Figure 5

Common Physical and Cognitive Adaptations for CYP with ME/CFS



PHYSICAL ADAPTATIONS

- Reduced timetables (developed in collaboration with CYP and families)
- Rest breaks
- Access to quiet and comfortable rest spaces in school
- Exit passes to leave lessons in secondary schools
- Minimising travel within the school environment, particularly in secondary schools

COGNITIVE ADAPTATIONS

- Simplifying tasks
- Providing extra time
- Alternatives to writing, e.g. scribe, iPads, alternative activities
- Slower pace of lesson delivery
- Individualised lesson plans (responsive to individual cognitive needs and absences)
- In Norway: individualised academic progression plans, reduced assessments, optional assessments at home

Note. Based on evidence from Brigden et al. (2021), Clery et al. (2022), and Similä, Nøst, et al. (2021).

Adaptations to meet the cognitive needs of CYP with ME/CFS within school were predominantly described by primary school teachers within the UK literature (Brigden et al., 2021), although some families of secondary-aged students described a slower pace in lessons (Clery et al., 2022). In Norway, some CYP described receiving greater flexibility in their academic progression, individualised academic progression plans, fewer assessments, and the option of completing assessments at home (Similä, Nøst, et al., 2021).

When students were unable to attend school, access to online teaching and resources was viewed positively by families (Clery et al., 2022; Similä, Nøst, et al., 2021) and school staff (Similä, Rø, et al., 2021). This was described as particularly positive during the Covid-19 pandemic, due to shared experiences of online learning with peers and greater ease in communicating with teachers using direct messaging.

A phased return following prolonged absence was considered important by most adolescents and parents to avoid unsustainable participation levels due to ME/CFS symptoms (Clery et al., 2022). Establishing a routine with the same teachers and friends each day reduced the unpredictable nature of the school day and thus the energy exerted on coping with this (Clery et al., 2022). Specialist ME/CFS services were also helpful for advising on activity management within school for some (Clery et al., 2022), although these are not available in all areas of the UK.

2.5.4.2 Support for Social and Emotional Needs. When CYP were in school, social experiences were prioritised for some by including break times with peers within timetabling, organising contact with peers, and ensuring accompaniment during rest breaks (Brigden et al., 2021; Similä, Nøst, et al., 2021). Maintaining connections was challenging when CYP were unable to attend school (Similä, Rø, et al., 2021), though primary school teachers often reported attempting to facilitate contact with classmates, sending work and things from peers home, and videoconferencing (Brigden et al., 2021).

To promote supportive attitudes and behaviour, primary school teachers often expressed the importance of raising awareness about ME/CFS amongst peers (Brigden et al., 2021). However, this was frequently highlighted as an unmet need in secondary schools (Clery et al., 2022).

Primary school teachers reported emotional support, including discussing CYP’s emotions, challenging negative thoughts, building self-esteem, and encouraging relaxation and mindfulness (Brigden et al., 2021). This contrasted with an absence of emotional support from school being cited within descriptions from other participant groups or studies. This contrast may stem from sampling bias, where particularly supportive teachers were more likely to participate, or social desirability, where they potentially overemphasised emotional support. Alternatively, differences may indicate that primary school structures facilitate greater levels of emotional support compared with secondary schools, the phase which most other studies focused upon.

2.5.4.3 Experiences of Support. Positive experiences of support in school have been associated with greater levels of attendance (Similä, Nøst, et al., 2021), wellbeing, and psychosocial functioning for this group (Similä et al., 2020). However, adolescents, families, and healthcare professionals described varying levels of school support internationally (Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021).

Just five of the fourteen families interviewed by Clery et al. (2022) were able to share positive examples of school support, and many families have described difficulties accessing education and support. All participant groups posited that a lack of school support hindered school experiences (Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021).

Most research exploring support in schools for CYP with ME/CFS is based on interviews with professionals. Social desirability and sampling bias within this research may mean that the support described may not be representative of all experiences. The scant published research exploring CYP's perceptions highlights a gap between professional reports (e.g. Brigden et al., 2021) and CYP's experiences (e.g. Clery et al., 2022). For example, CYP and parents described experiences of support that were promised but failed to materialise (Clery et al., 2022).

The literature indicates key facilitators and barriers to positive experiences of support in school: staff-student relationships, joined up care, knowledge and understanding, and attitudes and disbelief.

2.5.4.4 Staff-Student Relationships. Good communication with teachers and the wider school community was a key factor in determining satisfaction with school experiences in Norway (Similä, Nøst, et al., 2021). While the study characterised this as an absence of disbelief and distrust from teachers, it lacked a clear definition of good communication, perceptions of which may vary. Further Norwegian research highlighted difficulties in maintaining staff-student communication during periods of absence (Similä, Rø, et al., 2021).

Positive and close staff-student relationships and approaches which were individualised, flexible, proactive, and strength-based were reported to facilitate school engagement, school connectedness, and confidence to manage symptoms in school (Brigden et al., 2020; Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021). In primary schools, class teachers described close and consistent relationships with pupils which they felt positioned them well to support CYP with ME/CFS (Brigden et al., 2021).

Staff listening to the voice of the child was considered important to improve support within school (Brigden et al., 2020; Clery et al., 2022). However, primary school teachers often raised concerns that CYP with ME/CFS had difficulty expressing their feelings, needs, and preferences (Brigden et al., 2021). This necessitated supportive communication strategies, such as regular check-ins and tools and techniques like feelings card systems (Brigden et al., 2020; Brigden et al., 2021). In secondary schools, some adolescents utilised card systems to communicate their needs, to support them with taking a break from or leaving lessons as required (Clery et al., 2022).

2.5.4.5 Joined Up Care. Three-way communication and integrated care between families, schools, and health services were considered critical for arranging support and facilitating positive school experiences (Brigden et al., 2020; Clery et al., 2022; Similä, Rø, et al., 2021). Challenges arose when communication between systems was poor or there were disagreements about priorities.

In the UK, the use of a medicalised model within schools, where medical confirmation of the diagnosis was often required before support was implemented, was associated with difficult experiences early in CYP’s journeys with ME/CFS (Brigden et al., 2020; Brigden et al., 2021). Teachers and families largely viewed diagnosis as a catalyst to concerns being taken seriously by schools and support implemented (Brigden et al., 2020; Brigden et al., 2021; Similä, Rø, et al., 2021); this was often due to the validation associated with diagnosis, enhanced understanding of CYP’s needs, and ME/CFS services’ authority to enforce recommendations (Clery et al., 2022; Similä, Rø, et al., 2021). Despite this, two studies found divergent views about the impact of medical evidence on access to support; while some felt that its associated authority prompted school action, others experienced no change post-diagnosis (Clery et al., 2022; Similä, Nøst, et al., 2021).

Joint work between education and health professionals was considered helpful for supporting assessment prior to diagnosis, resource sharing, educating schools on support needs, negotiating appropriate support, and advice-giving about individual needs of CYP through direct contact, particularly in complex and severe cases (Brigden et al., 2020; Clery et al., 2022; Parslow et al., 2017; Similä, Rø, et al., 2021). However, there was consensus surrounding difficulties in enacting joint work (Brigden et al., 2020; Clery et al., 2022). Some teachers called for more direct communication between schools and clinicians for training and individualised guidance (Brigden et al., 2020).

Effective home-school communication was also considered important, whereby parents explained the condition and their child’s needs, provided updates, and support plans were developed collaboratively between parties (Brigden et al., 2020). Clinicians also emphasised the importance of empowering parents to liaise with school regarding arrangements for support for their CYP, although they recognised that some fractious relationships required them to intervene (Brigden et al., 2020).

2.5.4.6 Knowledge, Understanding, Attitudes and Disbelief. Where teachers had knowledge and experience in ME/CFS, families felt that CYP were better supported in school (Clery et al., 2022). However, there was a consensus between perspectives within the UK and internationally that a lack of awareness and understanding about ME/CFS amongst health professionals, schools, peers, and wider society hindered positive experiences (Ali et al., 2019; Brigden et al., 2021; Parslow et al., 2017; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021). This was a barrier to concerns being taken seriously, access to education, appropriate expectations being placed upon CYP, and implementation of appropriate and evidence-based support (Ali et al., 2019; Brigden et al., 2021; Parslow et al., 2017). Teachers and families, therefore, called for more training, support, and resources to develop understanding amongst school staff and peers (Brigden et al., 2021; Clery et al., 2022).

Feeling misunderstood, disbelieved, or delegitimised by schools, peers, and wider society hindered positive experiences, as reported by parents and CYP (Ali et al., 2019; Clery et al., 2022; Similä, Nøst, et al., 2021; Winger et al., 2014). Adolescents felt as though they had to justify their condition to peers, and some families felt as though schools withheld support due to disbelief (Clery et al., 2022). In Norway, adolescents stipulated that stigma and misunderstanding around ME/CFS were a key contributor to this (Winger et al., 2014). The impact of disbelief was reflected in an interview study with primary school teachers in the UK, two of whom reported scepticism regarding ME/CFS diagnoses, implementing only minimal adaptations like maintaining contact and sending missed schoolwork home (Brigden et al., 2021).

2.5.5 Synthesis of Findings from Theses

The two theses included in this literature review (Davies, 2021; Lewis, 2022) were largely consistent with themes generated from published journal articles.

2.5.5.1 Physical and Cognitive Symptoms. CYP within both studies described similar physical and cognitive symptoms affecting their needs within school, compared with the published literature (Davies, 2021; Lewis, 2022). These were a source of frustration for many CYP and led to a sense of disempowerment within narratives due to the control that ME/CFS exerted over activity and participation levels (Lewis, 2022). Subjectivity and potential researcher bias must be considered in relation to the interpretation of findings, although Lewis (2022) did use member checking for some aspects of analysis to support the credibility and trustworthiness of findings.

2.5.5.2 Social, Emotional, and Mental Health. Similar to published research, the theses highlighted experiences of social isolation and exclusion due to the impacts of ME/CFS on school and social participation and limited understanding and disbelief from peers (Davies, 2021; Lewis, 2022). The social pressure associated with not wanting to draw attention to their condition prevented some adolescents from being able to express their authentic selves and share their thoughts, feelings, and experiences (Davies, 2021).

Unlike the published research, some CYP in these studies described positive experiences of social support from close friends, facilitated by commitment and understanding and contact through social media (Davies, 2021). Even in cases of positive social relationships, however, social identity could suffer, as two CYP expressed negative perceptions of themselves as friends due to the impacts of ME/CFS on their capacity for social participation (Davies, 2021).

Extending on the published literature, one CYP in Davies' (2021) thesis retrospectively reflected on the emotional strain of managing ME/CFS symptoms and school-related stress and anxiety in school. This exacerbated symptoms and difficulties with school participation.

2.5.5.3 School Functioning. School attendance and absences were a common theme amongst theses, as with published research, impacting school belonging and connectedness (Davies, 2021; Lewis, 2022). A novel contribution from CYP within one thesis was a focus on hidden forms of non-attendance, such as not being well enough to actively engage in learning despite being physically present (Davies, 2021).

Difficulties with fatigue, memory, concentration, the process of learning, and missed lesson content made it hard for some CYP to keep up academically within school and manage the full range of curriculum subjects (Davies, 2021). Managing exams appeared to be a key concern amongst CYP within both studies (Davies, 2021; Lewis, 2022).

Aspirations from professionals, parents, and CYP themselves were often reduced (Davies, 2021; Lewis, 2022). This was experienced differently; whilst some participants found it acceptable in the context of their wider experience, others felt limited and disappointed by this, worrying about the impact on future opportunities and experiencing knock-on effects on self-esteem.

2.5.5.4 School Support. The theses contributed a more in-depth exploration of CYP's experiences of support. Adaptations were often felt to be inappropriate for CYP's needs (Davies, 2021). For example, physical spaces for rest were often not entirely comfortable or relaxing, and work sent home was often inconsistent and lacked the quality of in-class teaching. School support also often failed to acknowledge the social and emotional needs of CYP with ME/CFS.

The theses similarly highlighted the importance of staff-student relationships characterised by compassion, understanding, and good communication[14] (Davies, 2021; Lewis, 2022). However, a failure to listen to pupil voice and implement person-centred care led to experiences of broken trust and feeling disempowered for some (Davies, 2021; Lewis, 2022). Competing priorities between systems were described, with school concerns related to league tables often prioritised above the needs, preferences, and future aspirations of individual CYP (Davies, 2021).

Findings from the theses contributed an understanding of the advocacy role adopted by parents and CYP to ensure that needs were met (Davies, 2021; Lewis, 2022). Self-advocacy was experienced differently in terms of CYP's confidence with this (Davies, 2021). Tensions associated with having to challenge authority figures within school, conflicting with typical expectations of students, were highlighted.

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[14] Lewis (2022) characterised positive communication as comprising active listening and viewing CYP as expert in their illnesses.

A novel contribution of both studies, perhaps influenced by the researchers' roles as Trainee EPs, was the discussion about EHCPs (Davies, 2021; Lewis, 2022). These reportedly took a long time to obtain but facilitated access to important support, such as home tuition, which enabled access to learning whilst conserving energy otherwise spent navigating the school environment (Davies, 2021).

As with much of the published research, a lack of awareness and understanding about ME/CFS and associated needs, as well as disbelief about the condition, was considered to have negatively affected experiences and support received by CYP within school (Davies, 2021; Lewis, 2022).

2.6 Literature Review Conclusions and Implications

The current literature highlights the profound impacts of physical and cognitive symptoms of ME/CFS on social and emotional wellbeing and various aspects of school functioning for CYP with ME/CFS.

Social isolation, exclusion, and mental health difficulties often stem from reduced participation and a lack of understanding and disbelief from peers. School-related stress and anxiety related to academic functioning and managing symptoms within school were frequently described. These factors exacerbated symptoms and difficulties with school functioning.

School attendance was low due to difficulties with participation, despite being prioritised highly. Hidden forms of non-attendance meant that even when CYP were in school, they were often unable to participate equally. This led to academic struggles and concerns about exams and future aspirations, whilst also reducing school connectedness and quality of school life.

Additional support in school was, therefore, considered crucial to meet physical, cognitive, academic, social, and emotional needs. Physical adaptations were common, with some cognitive supports described, but social and emotional needs were widely overlooked, particularly in secondary schools. The quality of staff-student relationships, communication between different aspects of CYP’s systems, and knowledge, attitudes, and beliefs from staff and peers related to ME/CFS widely mediated difficulties accessing education and support.

Current research highlights the importance of supporting CYP with ME/CFS in school. However, gaps in research exploring experiences from CYP’s perspectives were highlighted. Whilst consideration of multiple perspectives is a strength in the evidence base, issues related to sampling bias and social desirability mean that there may be a gap between experiences described by professionals and the lived experiences of CYP. This necessitates the amplification of CYP voices in this area.

From a UK perspective, research exploring the school experiences of CYP with ME/CFS remains limited. While existing UK-based studies highlight challenges to school functioning, particularly related to physical and cognitive symptoms, few offer in-depth exploration of CYP’s lived experiences, especially concerning social and emotional dimensions and experiences of support. The scarcity of UK-based research that foregrounds CYP voices highlights the need for further work in this area to better understand educational experiences and support for this group in UK contexts.

Furthermore, most of the evidence within this review has drawn upon studies exploring general experiences of CYP with ME/CFS, which may not provide a comprehensive view of school experiences. Current UK-based studies designed to focus exclusively on school experiences from the perspective of CYP with ME/CFS (Davies, 2021; Lewis, 2022) are based on very small sample sizes and have limited transferability, due to focusing on individual experiences. Further research is therefore required to explore patterns and common themes, from the perspective of CYP with lived experience, to inform school support and to improve school participation and quality of life in school for CYP with ME/CFS.

Furthermore, little is known about the intersection between aspects of identity and ME/CFS experiences. Further research, representing a diverse sample of CYP with ME/CFS, is necessary to explore this.

2.7 Chapter Summary

This literature review sought to answer the question, ‘What does the existing literature tell us about the school experiences of CYP who have ME/CFS?’. The use of a systematic approach facilitated a comprehensive understanding of existing evidence and gaps, providing a context and rationale for further research. Thirteen articles were identified that explored the school experiences of CYP with ME/CFS, from a range of perspectives. The research highlighted difficulties associated with school functioning and a need for physical, cognitive, academic, social and emotional support. However, the review found limited evidence to illuminate CYP's experiences of such support within a UK context. The current study will therefore seek to explore the experiences of CYP with lived experience of ME/CFS during secondary school, including ways in which they were supported, in order to gather insights about how educational professionals can better support them.

3. Methodology

3.1 Chapter Overview

This chapter will outline the aims, purpose, and RQs posed by the current research. The ontological and epistemological positions will be discussed, forming the underpinning for research design, sampling, and data collection methods. Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022) was chosen as the analytical method; the rationale for this, including alternative analytical methods considered, is described, followed by an overview of the approach. Ethical considerations are discussed, including how scientific rigour was ensured through research quality.

A reflexive journal was used as a tool to log reflections throughout the research process, including reflections on the researcher's identity and positioning, subjective experiences, and the influence of these on the research (Braun & Clarke, 2022). Extracts from this diary are embedded throughout this thesis to enhance transparency in demonstrating the researcher's position, thoughts, assumptions and decision-making.

3.2 Research Purpose and Questions

The literature review highlighted a need for further in-depth exploration of the school experiences of CYP with ME/CFS, specifically regarding experiences of support.

This research had an exploratory purpose (Robson & McCartan, 2016). It aimed to explore the secondary school experiences of CYP with ME/CFS, including experiences of support. In doing so, it sought to gather insight regarding ways in which educational professionals can better support them.

RQs provide the underpinning for most decisions within research (Robson & McCartan, 2016). Braun and Clarke (2022) suggest that RQs should be broad to keep the scope of RTA open at an early stage, whilst ensuring clarity regarding what the research intends to provide insight into. Given the exploratory nature of this research, ‘what’ questions were considered suitable for seeking descriptive insights (Blaikie, 2007). The following overarching questions were developed to be addressed by the current research:

1. *What are the experiences of CYP with ME/CFS during secondary school?*
2. *What are CYP’s experiences of support at secondary school whilst living with ME/CFS?*

These questions were considered sufficiently broad to explore a range of experiences without imposing restrictive assumptions regarding the nature of these.

3.3 Research Orientation

3.3.1 Ontology

Ontology is concerned with the nature of reality and being (Crotty, 1998). It helps researchers to consider the level of certainty they can have regarding the nature and existence of objects they are researching (Moon & Blackman, 2014). Two polarised ontological positions are realism and relativism (Moon & Blackman, 2014). Realism conceptualises that there is a single objective reality which can be studied, understood, and experienced as an absolute ‘truth’. Contrastingly, relativism posits that there are multiple realities or ways of thinking about something. In accordance with relativist ontology, reality is constructed within the human mind, relative to individual experiences at a given place and time.

Critical realism sits between these two positions (Maxwell, 2012). It views the nature of reality as existing independently of human thought, whilst recognising the impact of context on the understanding and experience of phenomena (Moon & Blackman, 2014). Reality is therefore considered singular, although different perspectives, interpretations, and representations of this, influenced by language and culture, are acknowledged (Maxwell, 2012). Fletcher (2017) described three levels of reality within critical realist ontology: the empirical level, which represents events as we experience or interpret them; the actual level, where events occur without the filter of human experience; and the real level, where causal mechanisms exist, which produce events. This multi-layered perspective makes critical realism well-suited for analysing social problems and developing recommendations for social change, as it facilitates exploration of underlying causes and systemic influences (Fletcher, 2017).

This research adopted a critical realist ontological stance. This position recognised ME/CFS as a real neurological condition that exists independently of how it is perceived or experienced by individuals. It also acknowledged the significant impacts of contextual factors on shaping the experiences of CYP with ME/CFS in secondary school. This facilitated exploration of subjective school and support experiences and the systemic factors contributing to these.

3.3.2 Epistemology

Epistemology considers “how we know what we know” (Crotty, 1998, p. 8). It deals with the nature of knowledge, how it is created, and what is possible to know (Al-Saadi, 2014). In research, epistemology therefore dictates how knowledge can be studied or produced, as different methods are required depending on whether knowledge is considered to exist in an objective, certain way, or is value-laden. Three common epistemologies within qualitative research are (post)positivism, contextualism and constructionism (Braun & Clarke, 2022).

(Post)positivism is a refinement of positivism, which assumes there is one reality which can be known through objective, value-free inquiry (Ormston et al., 2014), which should be strived for, despite recognition that observations cannot be ‘pure and perfect’ (Haraway, 1988). At the opposite pole, constructionism suggests that research practices produce evidence (Braun & Clarke, 2022). Language is a central focus of constructionist research as it posits that realities are created by ways of talking and writing about them. Knowledge is argued to be socially constructed and thus historically and culturally situated, with no ultimate truth.

Contextualism (Pepper, 1942) recognises that multiple accounts of reality may exist due to the influence of context upon humans (Tebes, 2005), leading knowledge to be viewed as partial, provisional and situation-dependent (Jaeger & Rosnow, 1988). Since knowledge cannot be separated from the knower in a contextualist epistemology, emphasis is placed upon the relationship between researcher and participant and the co-production of meaning. Reflexivity is, therefore, crucial to illuminate the researcher's role and the context within which the knowledge was produced (Madill et al., 2000).

This research adopted a contextualist epistemology, recognising that knowledge produced about experiences of CYP with ME/CFS in secondary school is deeply influenced by contextual factors such as education and healthcare systems, cultural beliefs and societal attitudes at the current time. Consequently, insights from this research were understood as being shaped by contextual influences and not universally generalisable. Reflexivity was crucial to consider the role of the researcher's beliefs, assumptions, and positionality and how this may have shaped interactions with participants and the interpretation of the data.

3.3.3 Reflexivity

Reflexivity involves turning the 'researcher lens' onto oneself as it acknowledges the role of the researcher in knowledge production (Berger, 2015). It demands reflection upon assumptions, expectations, decisions, and actions throughout the research process (Finlay & Gough, 2003) to consider what these may enable, exclude, or close off (Wilkinson, 1988).

Reflexivity requires ongoing critical self-evaluation of one's positionality and how this may affect the research process and outcomes, attending to personal characteristics, beliefs, biases, ideological stances, and emotional responses to participants (Berger, 2015). Therefore, locating oneself as the researcher was critical in clarifying how the researcher’s personal characteristics and context may shape research and analysis. A reflexive journal and regular research supervision were used to consider the researcher’s experiences, beliefs, and personal values, which likely impacted this research (Braun & Clarke, 2022). The diary extract in Figure 6 provides some insight into the researcher’s position and the influence of this upon the research.

As described in the diary extract, the researcher identified as an insider-outsider researcher (Hellawell, 2006), balancing lived experiences with feeling like an outsider to the ME/CFS community following recovery. Lived experience of ME/CFS afforded the researcher a greater level of understanding of the lives of the participant group to support ethical representation (Bridges, 2001). Meanwhile, outsider status enabled the researcher to stand back and consider a range of alternative perspectives (Simmel, 1950).

Figure 6

Reflexive Diary Extract 2

Personal Reflexivity: My positioning in relation to ME/CFS

I come to this research as someone with lived experience of ME/CFS in childhood myself. I remember very little of the period of my life where I experienced ME/CFS, just snippets of coming home from school feeling so unwell, the emotional impacts, and so badly just wanting to be able to do normal things like go to school for a full day. Despite my limited memories, ME/CFS did significantly impact both my and my family's life. I count myself as one of the few lucky ones, as I was able to access a specialist ME/CFS service and I was able to recover. From reading and hearing about others' experiences, however, I am highly aware that supportive experiences are not widespread. Given these experiences, I have a strong personal connection to the topic. I must remain cautious not to over-identify with participants or emphasise experiences that align with my own. I am also mindful that whilst my experiences will support me to empathise with participants, it is likely that I will be interpreting their experiences through my own lens, so reflexivity throughout the interview and interpretation process will be crucial. I'll need to keep revisiting this in research supervision.

Although partially an insider to this research, my current status leads me to consider my outsider status in equal balance. Having recovered from ME/CFS a long time ago, embarking on this research journey, I feel like an outsider to the ME/CFS community. I have reflected on how I had suppressed memories of the period of my life affected by ME/CFS. I wonder whether societal attitudes towards the condition and the desire to push down distressing emotions and memories contributed to this. Due to this, as a researcher, I notice that I am particularly alert to the role of sociocultural context and emotional narratives within experiences.

3.4 Choosing a Methodological Approach

3.4.1 Qualitative Methodology

In choosing a methodological approach, theoretical assumptions related to the ontological and epistemological stance were considered (Braun & Clarke, 2022). Qualitative research uses words as data to generate rich, in-depth insights and thick descriptions (Willig, 2019). It facilitates understanding related to the nature, quality and meaning of human experience (Miller, 2016), whilst remaining sensitive to contexts in which the data is gathered (Braun & Clarke, 2013). A qualitative approach was chosen as it aligns with the ontological and epistemological stance adopted within this research; qualitative methodologies facilitate exploration of subjective experiences and meanings within specific contexts, rather than seeking objective, measurable truths.

3.4.2 Overview of Reflexive Thematic Analysis

A range of qualitative approaches for analysis were considered. RTA (Braun & Clarke, 2022) was considered best suited to address the current research purpose, questions, and positionality. This section will provide an overview of Thematic Analysis (TA), leading towards the focus on RTA and the rationale for its selection.

3.4.2.1 Thematic Analysis. TA is concerned with patterns of meaning and offers a method for developing, analysing and interpreting patterns across a qualitative dataset (Braun & Clarke, 2022). TA has long been used within qualitative research. However, it was “poorly demarcated and rarely acknowledged” (Braun & Clarke, 2006, p. 77) prior to the publication of Braun and Clarke’s (2006) seminal paper, which provided a detailed TA procedural guide. Since then, it has been considered as a ‘fuzzy set’ (Madill & Gough, 2008) of approaches which share a primary interest in identifying and making sense of patterns within data, but differ according to their paradigmatic and epistemological values and procedures (Braun & Clarke, 2021c). Braun and Clarke (2019) clustered TA into three different versions, namely coding reliability, codebook, and RTA.

3.4.2.2 Reflexive Thematic Analysis. Virginia Braun and Victoria Clarke developed RTA from TA to emphasise reflexivity and the active role of the researcher in shaping interpretations (Braun et al., 2019). RTA aligns with a qualitative paradigm and is a commonly used method for analysing patterns across a dataset in order to understand and tell interpretative stories about meanings (Braun & Clarke, 2023). This approach was deemed suitable for exploring experiences and the meanings made of these, related to secondary school experiences with ME/CFS, in this study.

RTA values the subjective role of the researcher as an analytical resource, rather than viewing it as a source of bias to be controlled (Braun & Clarke, 2022). Reflexivity is, therefore, central to RTA to support researchers in understanding and owning their perspectives (Elliott et al., 1999). A reflexive approach was considered useful within the current research to facilitate critical engagement with interpretations, recognising the influence of the researcher’s assumptions, theoretical lens, and interactions with the data. This was particularly important given the researcher’s insider-outsider status and the extent of dismissive attitudes, stigma and misconceptions often experienced by people with ME/CFS (DHSC, 2024).

RTA is a theoretically flexible approach, although it emphasises the influence of paradigmatic, epistemological and ontological positioning on analysis (Braun & Clarke, 2019). It is considered well suited to the critical realist/contextualist orientation adopted within the current research as it acknowledges that meaning and knowledge are situated and contextual (Braun & Clarke, 2022). Thus, it was suitable for exploring CYP’s subjective experiences in school, whilst acknowledging the influence of broader contextual factors in shaping these.

3.4.2.3 Critique of Reflexive Thematic Analysis. Despite thorough delineation regarding methods for conducting TA, ‘unknowing practice’ regarding RTA is common (Braun & Clarke, 2023). Reviews of the use of RTA have highlighted frequent methodological incongruences within research and an absence of sufficient explanation where diversions from common practice are made. Over time, Braun and Clarke (2024) have refined their guidance and developed recommendations for researchers to facilitate methodological congruence and knowing practice. To ensure the quality of RTA within the current study, the researcher followed these recommendations. For example, a thorough reading of methodological literature (e.g. Braun & Clarke, 2022) and worked examples (e.g. Byrne, 2022) supported a sound understanding of the approach and discussions within research supervision supported reflections on subjectivity and theoretical assumptions within knowledge generation.

A further critique of RTA is that it can be difficult to capture and draw attention to the complexities and contradictions between individual participants’ accounts, due to its cross-case orientation (Braun & Clarke, 2022). The current study used a small data set of six participants, which enabled greater attention to differences between accounts, and the researcher attempted to acknowledge variations within themes throughout.

3.4.3 Alternative Analytical Methods

This section will outline three alternative approaches to analysis that were considered, addressing their compatibility with the research aims.

3.4.3.1 Interpretative Phenomenological Analysis. IPA is a qualitative analytical approach which explores personal lived experiences and how individuals make sense of them in-depth (Smith et al., 2022). Rooted in phenomenological philosophy and hermeneutic theory (Eatough & Smith, 2017), IPA is an experiential approach. It focuses on both experiences themselves, and the interpretative processes used to generate meaningful insights about phenomena. It is considered valuable for exploring lived experiences and providing subjective psychological insights (Eatough & Smith, 2017).

However, IPA was not chosen for the current research. Its idiographic approach and focus on nuanced, personal interpretations do not align with the study's aim of identifying patterns in experiences to inform broader, actionable implications for supporting students with ME/CFS (Braun & Clarke, 2021a). Additionally, the focus on individual meaning-making within IPA may not adequately address external contexts and systemic issues, which are central to this study's contextualist epistemological stance.

3.4.3.2 Narrative Analysis. NA views personal stories as “the primary form by which human experience is made meaningful” (Polkinghorne, 1988, p. 1). It offers a methodology for exploring how individuals make sense of the world and themselves by focusing on their narratives, considering content, form, and structure (Murray, 2015). NA aims to preserve the integrity of stories told by participants by considering the narrative as a whole, as well as in relation to its constituent parts and sociocultural context (Josselson & Hammack, 2021). In doing so, it amplifies often unheard or misunderstood voices (Woodcock, 2016). Due to this, NA has been increasingly valuable in exploring medical condition lived experiences (McLeod, 2011), including CHCs in CYP (Crossley, 2000).

However, NA was not chosen for this research because its focus on individual stories may not effectively capture broader themes common across groups of CYP with ME/CFS. Identifying shared patterns was necessary to inform how educational professionals can better support these students, making another methodology more suitable.

3.4.3.3 Grounded Theory. Grounded theory is an analytical approach that aims to develop theory inductively from data, making it well-suited for generating explanations of observed phenomena (Tie et al., 2019). It therefore aligns with explanatory research purposes (Charmaz & Henwood, 2017).

Grounded theory was not considered suitable for the current research. Some theoretical contributions regarding experiences of CHCs in education already exist, including a study on ME/CFS experiences in schools in Norway, which offers relevant insights regarding factors associated with positive and negative experiences in educational contexts (Similä, Nøst, et al., 2021). As such, this research focused not on constructing new theory with an explanatory purpose, but on exploring experiences and identifying support needs to address gaps in the existing evidence base regarding ME/CFS school experiences. Furthermore, the sample within the current study was relatively small, thus more suited to RTA (Braun & Clarke, 2021a).

3.5 Research Participants

3.5.1 Composition and Size of the Dataset

RTA offers flexibility regarding the composition of datasets; it can accommodate heterogeneous or homogeneous samples, depending on the purpose of the research (Braun & Clarke, 2022). Purposive sampling is the typical approach adopted within qualitative research as it facilitates insight and in-depth understanding (Patton, 2002). It involves the selection of “information-rich” (Patton, 2002, p. 230) cases which contribute insights related to the key matters relevant to the research purpose. Given that the current research aimed to explore lived experiences, a purposive sampling approach was considered best suited to recruit participants who shared the experience of having ME/CFS during secondary school.

Sample size is a complex consideration (Sandelowski, 1995) and should account for research purpose, aims, usefulness, credibility, and feasibility given available time and resources (Patton, 2002). Due to problems associated with determining sample sizes based upon data saturation (Braun & Clarke, 2021e), Braun and Clarke (2022) propose consideration of information power instead (Malterud et al., 2016). This prioritises reflection on the richness of a dataset and the extent to which it is appropriate for the aims and requirements of the study.

This research aimed to obtain a sample of six participants. This aligned with Braun and Clarke’s (2013) suggested approach for a small- to medium-sized project and their suggested minimum sample size for TA (Braun et al., 2016). It was deemed sufficient to facilitate in-depth interviews to explore the RQ and generate rich, detailed, and nuanced data (Braun & Clarke, 2022). Meanwhile, this sample size was feasible given the time and resources available for a professional doctoral thesis and anticipated recruitment challenges, following difficulties with recruitment reported within similar projects (Lewis, 2022).

3.5.2 Participant Criteria

This study sought to recruit CYP aged 16 to 25 who reported as having had a diagnosis of ME/CFS lasting at least 3 months during secondary school[15]. The participant inclusion criteria and rationale are detailed in Table 4.

Table 4

Participant Inclusion Criteria

Participant Criteria	**Rationale**
Aged between 16-25 years old	Participants were required to be aged above 16 so that they had completed their secondary education and were able to reflect upon this retrospectively. The upper limit of 25 ensured that secondary experiences remained relatively recent and facilitated retrospective insights on experiences after formal education. Working with CYP aged up to 25 is a key role in EP practice, highlighted by the SEND Code of Practice (DfE & DHSC, 2015).
Had a diagnosis of ME/CFS of at least 3 months' duration during secondary school	Focusing upon a singular phase of education facilitated a more targeted understanding of experiences within secondary school systems and at this unique stage of development. The secondary education phase was of interest due to a peak incidence of ME/CFS occurring between the ages of 10 and 19 (Bakken et al., 2014), covering predominantly the secondary age range. Furthermore, the literature review highlighted a paucity of published research within the UK exploring secondary school experiences for this group.

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[15] Participants were not required to provide formal evidence of their diagnosis. Instead, they were asked to self-report that they met this inclusion criterion.

Participant Criteria	Rationale
	Having a diagnosis of ME/CFS for at least 3 months was deemed necessary to ensure lived experience and since 3 months' duration is the time required for diagnosis (NICE, 2021).
Able to communicate verbally in English	Participants needed to be able to express themselves verbally in interviews with the researcher who only spoke the English language.

3.5.3 Recruitment

Recruitment was completed via ME/CFS organisations and social media. Participation was self-selected and voluntary, with participants selected on a first-come, first-served basis. A research recruitment poster (Appendix F), providing information about the study and researcher contact details, was shared with CYP meeting the inclusion criteria through relevant charities, organisations, support groups and social media pages who agreed to support the research by advertising the study. Participants opted into the research voluntarily by contacting the researcher via email.

Given the impacts of ME/CFS on physical and cognitive functioning, the researcher attempted to encourage the participation of potentially 'difficult to engage' groups (Braun & Clarke, 2013) by explicitly advertising the option for reasonable adjustments to accommodate individual needs. Given the limited inclusion of the views of CYP with severe ME/CFS in existing research, it was hoped that this would support participation of CYP with a higher level of need.

The recruitment process began in the summer term of 2024, following ethical approval for this research being granted (Appendix G). The process began by initially contacting large nationwide charitable organisations for people with ME/CFS, asking them to share the poster with their networks. Limited responses from charities within this recruitment round led the researcher to extend the recruitment round to smaller charitable organisations and support groups in and around Greater London, where the researcher was based, as well as social media pages such as ‘X’. Reflections upon this process are included within Figures 7 and 8.

Figure 7

Reflexive Diary Extract 3

Reflections on Recruitment

Reflecting on the recruitment process thus far, I find myself grappling with some unanticipated challenges. Although I had anticipated some difficulties in recruiting young participants, the obstacles have emerged much earlier in the process, at the stage of gaining access through charitable organisations as gatekeepers.

The lack of engagement from national ME/CFS charities has left me feeling worried and disappointed. These organisations play a crucial role in the lives of many affected by ME/CFS, and I had hoped they would see the potential value of this research for the community. At the same time, I can empathise with the internal challenges they may be facing (limited resources, competing demands, and the need to carefully manage the wellbeing of those they support). This leads me to consider important questions: *How might I communicate the value of the study more effectively, aligning it with their own goals of systemic change? If my next recruitment phase is not successful, what other routes could I explore?*

In supervision, we discussed the role of my status as an insider-outsider researcher and how this might impact my experience of recruitment. Despite viewing myself as a partial insider, without any current connections to ME/CFS organisations or communities, difficulties with engagement were a stark reminder of my current outsider status.

Although I find myself feeling deflated, I am lucky that my research supervisor has been firmly holding the hope for me. With this in mind, I’m ready to embark on the next step of my recruitment plan, to contact local groups and organisations in the hopes that they will share my poster.

Figure 8

Reflexive Diary Extract 4

A Recruitment Breakthrough

This week has brought a much-needed breakthrough in recruitment. After weeks of uncertainty and setbacks, I received responses from a couple of national ME/CFS organisations and local support groups that saw the value in my research. Suddenly, there has been a flurry of interest from CYP willing to participate. I am experiencing immense relief and gratitude for people’s interest and the recognition of the importance of this research. I feel excited and deeply honoured that these CYP are willing to share their experiences with me.

Amid this excitement, I am conscious of the need to reflect on the diversity of the sample. Recruitment through smaller and more concentrated channels may shape the participant pool, for example as they are more likely to share certain sociocultural contexts. Nevertheless, I feel confident that RTA will enable the reflexivity necessary to thoughtfully account for the influence of context within my analysis.

As I move forward, I feel a renewed sense of responsibility to these participants. I hope to honour their contributions and create a meaningful space for their voices to shape a deeper understanding of their experiences and to effect real change and improvements to ensure that their generosity to this research has the impact it deserves.

When participants contacted the researcher, they were provided with participant information sheets (Appendices H and I) and the consent form (Appendix J). Participants were offered an optional preliminary Zoom call to discuss questions, concerns, or reasonable adjustments. No participants chose to take this up, although email communication was utilised to discuss these matters. The researcher checked that participants met the inclusion criteria and consent forms were returned to the researcher via email, before mutually convenient interview dates were arranged.

Fourteen potential participants contacted the researcher following advertisement through support groups and social media. Three did not meet the inclusion criteria, and five did not respond to the researcher after receiving information sheets.

A total of six CYP, aged 17 to 25, participated in the study. Participants were asked about their demographic information, which is presented in Table 5 for the purpose of transparency and context. All participants were female and five identified their ethnicity as White British, whilst one identified their ethnicity as Mixed (English and Colombian). Pseudonyms chosen by the CYP are used throughout this thesis.

Table 5

Participant Information

Participant	Age	School Year at Diagnosis	Gender	Ethnicity	Region
Kiara	18	Year 11	Female	White British	East of England
Jenny	17	Year 9	Female	White British	North East England
Florence	22	Year 9	Female	White British	Scotland (educated in South West England)
Freya	21	Year 11	Female	White British	East of England
Lucy	25	Year 9	Female	Mixed (English and Colombian)	East of England
Meredith	17	Year 11	Female	White British	East of England

The reflexive diary extract in Figure 9 notes the researcher's reflections on characteristics of the sample.

Figure 9

Reflexive Diary Extract 5

Reflections on the Sample

Looking at the sample of six participants, I am pleased to have gathered a group of young women who span the ages of inclusion within this research. This offers a valuable opportunity to explore the experiences of females with ME/CFS during a critical period of their lives. I am wary, however, that the diversity of my sample is limited in relation to gender, ethnicity and geography. The challenge moving forward is to remain aware of the voices that may not be fully represented, and to ensure that I approach the analysis with an openness to complexity within shared categories.

As a White British female researcher, I am also conscious of these shared visible aspects of identity with my participants. This may facilitate a sense of familiarity and support rapport, but also carries the risk of overlooking less familiar perspectives, assuming understanding, or leading to blind spots. My own experiences and positionality influence how I interpret the data, and it’s important to remain reflexive about how these intersecting identities (both mine and participants') shape the research process. Research supervision and reflexive journalling will be crucial to support this, and my ontological and epistemological positioning facilitates exploration and acknowledgement of this.

3.6 Data Collection

3.6.1 Retrospective Design

A retrospective design was chosen for data collection to enable deeper reflections on the entirety of secondary school experiences, offering a more complete picture of experiences and sense-making related to this. Furthermore, by gathering data from participants at a later developmental stage, it was considered that they would be more likely to be able to engage in rich discussions about their experiences and support needs due to differences in cognitive, linguistic, psychological, and social competencies (Garbarino & Stott, 1989; Irwin & Johnson, 2005).

Sandelowski (1999) highlighted the centrality of temporality in qualitative research, as data collection captures participants' experiences and meaning-making at a moment in time (Braun & Clarke, 2021b). Therefore, analysis and interpretation considered potential reinterpretations and reframing of experiences that are likely to occur over time as contexts change, as well as issues related to memory, recall bias, and temporal distance that may also influence what was retrospectively accounted. The contextualist epistemological stance adopted within this research facilitated the acknowledgement of this.

3.6.2 Semi-structured Interviews

A wide variety of data collection methods are considered appropriate for RTA (Braun & Clarke, 2013). To answer the RQ, it was deemed that semi-structured interviews would be appropriate to provide thick data, which is rich, in-depth, and nuanced (Braun & Clarke, 2022).

While focus groups were considered, interviews were considered more appropriate for exploring individuals' experiences in more depth. Interviews allowed for diverse experiences to be shared without pressures to conform to the majority opinion due to group dynamics, and regarding a subject in which participants had a personal stake (Braun & Clarke, 2013). Individual interviews also facilitated responsiveness to individual physical and cognitive needs associated with ME/CFS symptoms and reduced pressure on participants to exert themselves in a group discussion.

A semi-structured approach, using open-ended questions, enabled participants to talk at length about their experiences and maintained flexibility to adapt questions based on participants' responses (King et al., 2019; Robson, 2011). This facilitated rapport and the generation of rich data (Smith & Osborn, 2015). Furthermore, a semi-structured approach provided increased structure to support participants to coherently articulate their stories, responsive to common cognitive needs associated with ME/CFS (Rowe et al., 2017). This followed previous research highlighting difficulties experienced by CYP with ME/CFS in constructing and sharing narratives (Lewis, 2022). Interviews comprised a Grid Elaboration Method (GEM) activity and further semi-structured questioning (Appendix K).

3.6.3 Grid Elaboration Method

Principles of free association methodology and the GEM (Joffe & Elsey, 2014) were utilised within semi-structured interviews. The GEM is underpinned by psychoanalytic theory related to unconscious defence mechanisms (Hollway & Jefferson, 2000). It was developed to support the pursuit of emotive and experiential content beyond the often intellectualised responses elicited within semi-structured interviews, using free association drawing or writing techniques (Hollway & Jefferson, 2000). This approach involves presenting participants with a blank grid of four boxes and instructing them to draw and/or write one image, word, or phrase in each box which they associated with a topic. It has previously been used in research with 19 to 25-year-olds and described as a positive experience (Newman, 2020; Park, 2018).

Adoption of principles of the GEM within this research facilitated participant-led elicitation of participants' thoughts and feelings related to the topic of ME/CFS in secondary school. Using the structure and visual cue of the grid, this data collection method was responsive to cognitive needs associated with ME/CFS, such as brain fog, thus supporting engagement and narration of experiences. Additionally, redefining power relations was important within this research due to the misinformation, bias, and stigma surrounding ME/CFS (Hughes et al., 2023) and the limited research focusing on lived experiences. The GEM increased participants' control by facilitating a focus on issues most important to them, rather than solely areas salient to the researcher (Hollway & Jefferson, 2000).

At the start of the interview, participants were presented with a blank grid and asked to draw and/or write their personal associations to the experience of having ME/CFS in secondary school. This was intended to elicit four salient associations, which participants were then invited to elaborate on in turn. The researcher used open probing questions to enquire about these until the point at which participants had no further details to add, examples of which are included in Appendix K.

Due to the virtual nature of interviews, this study followed the online GEM procedure adopted by Keen et al. (2021). Prior to the interview, participants were sent a blank copy of the grid, without any instructions, and asked to print or copy the grid in preparation. Instructions were given verbally and written into the 'chat' function on Zoom during the interview. Time was provided to complete the grid, and participants were asked to either photograph their completed grid and email it to the researcher or hold it to the webcam to be screenshotted by the researcher prior to the elaboration stage (Appendix L).

3.6.4 Interview Schedule

Semi-structured interviewing followed the completion of the GEM activity. The semi-structured interview was based on an interview schedule (Appendix K). This schedule listed topics to be covered within interviews, with default wording for questions, although these were frequently modified based on the flow of the interview (Robson, 2011).

The interview schedule was designed based on the RQs, and questions were designed to be open, non-assumptive, empathetic and linguistically appropriate (Braun & Clarke, 2013). For example, participants were asked their preferred terminology for describing ME/CFS at the start of interviews and individual preferences were used throughout. The sequencing of questions was organised so that they flowed logically, and potentially sensitive questions were asked later in interviews to support the development of rapport first (Braun & Clarke, 2013). For example, a question related to personal identity was deemed important to explore how experiences may vary accordingly, but was not raised until after the mid-way point to support rapport development prior to this. A closing or ‘clean-up’ question was asked at the end to check whether participants had anything else they would like to add (Braun & Clarke, 2013). The interview schedule was reviewed between interviews to ensure that sufficient depth was facilitated within the data to facilitate meaningful and useful TA (Connelly & Peltzer, 2016), although no changes were deemed necessary.

Prompts and probes were considered within the interview schedule. Some specifying questions (Kvale & Brinkmann, 2009) were prepared and included within the schedule in italics, which could be used to seek further detail if necessary. For example, question two was designed to encourage participants to speak about challenges and difficulties they experienced with as little prompting as possible initially; however, more specific prompts were prepared in case participants experienced difficulty responding to the main question or gave a short reply (Smith & Osborn, 2015). Additional unplanned follow-up questions were also asked to explore participants' responses in greater depth.

3.6.5 Virtual Interviews

Interviews were conducted virtually to increase accessibility and reduce time and physical demands for participants, particularly due to the impacts of ME/CFS on functioning. Zoom video conferencing software was utilised primarily, in accordance with the Tavistock & Portman NHS Foundation Trust's video conferencing guidelines. Participants and the researcher joined Zoom interviews with their cameras on.

Although traditional face-to-face interviews are most common in qualitative social research (Al-Yateem, 2012) and are widely viewed as the 'gold standard' (Khan & MacEachen, 2022), online synchronous interviews address issues with accessing geographically dispersed populations, time and financial constraints, and accessing vulnerable groups who may otherwise have difficulty engaging in research (Khan & MacEachen, 2022). As interviews were remote, participants could choose to complete the interview in a confidential location in which they felt most comfortable, rather than an unfamiliar site. This was hoped to reduce anxiety levels and to rebalance power relations to some extent.

Telephone interviews were offered as an alternative when requested. This approach was adopted for Lucy due to limited access to a Zoom-enabled device. Based on Farooq and De Villiers' (2017) criteria, this was deemed suitable as collecting contextual data was not a priority, both parties were experienced in using telephones, and other computer-based technologies were inaccessible. Although this limited the ability to follow non-verbal cues in communication, the researcher ensured a successful telephonic interview through a well-thought-out interview guide and a relaxed and engaged interview style in which they listened carefully, clearly articulated questions, provided feedback and expressed interest verbally to support rapport (Farooq & De Villiers, 2017; Hermanowicz, 2002). However, since telephone interviews were offered in response to request and had not been planned within the original research design, they were not explicitly offered on participant information sheets; other potential participants preferring this method may have been excluded from this research due to this. Future research could enhance equity and accessibility by explicitly outlining a range of participation options within recruitment materials.

Establishing rapport was crucial to support participants to feel comfortable sharing their experiences within interviews. While challenges in virtual rapport-building have been noted (Cater, 2011), successful experiences of videoconferencing (Deakin & Wakefield, 2014) and telephone interviews (Vogl, 2013) have been described. To support this, the researcher developed engagement by communicating with participants via email several times before interviews and prioritising time at the start of interviews for informal chat so that participants felt comfortable being open and expressive (Al-Yateem, 2012; Deakin & Wakefield, 2014).

Despite the advantages of virtual interviews, the researcher did encounter challenges. Poor internet connection affected one interview, causing disruptions and leading the participant to reschedule (see Figure 10 for reflections on this experience). Additionally, since the researcher did not share the same physical space as participants, they missed the opportunity to observe participants' body language and emotional cues (Cater, 2011). Nevertheless, the analysis of purely verbal data collected within interviews was sufficient and fitting with RTA.

Figure 10

Reflexive Diary Extract 6

Reflecting on Technical Issues in a Virtual Interview

I was scheduled to interview Freya this morning, but Wi-Fi connectivity issues made the Zoom connection too unstable for a successful conversation. Although we briefly met and attempted the interview, the constant interruptions led us to agree to reschedule.

I believe this was the right decision... for Freya to be able to open up about her experiences and for me to properly listen, a stable connection is essential. Still, I left the experience feeling frustrated and worried about how this might affect Freya and her engagement with the research. It's a reminder of the unpredictability of online interviews, where technical issues can disrupt the process in ways beyond my control. I'm also reflecting on how this could have impacted the dynamic between us. Freya, understanding and proactive, offered to reschedule, which may have shifted the balance of power. While it gave her agency, I'm aware she may feel let down after preparing for today. Given the energy required for someone with ME to plan and participate, I feel guilty that she'll need to prepare again. That said, a positive outcome is that we've established some initial rapport, which may help when we reconnect later this week. I'm looking forward to hearing more from her.

3.6.6 Reasonable Adjustments

Reasonable adjustments were offered to support the engagement of participants who may otherwise struggle to participate in research. These were discussed prior to interviews to facilitate planning and ensure that a safe environment was created for participants from the outset.

Flexibility in scheduling was provided, enabling participants to choose suitable dates and times in recognition of the importance of pacing as a key activity management strategy for people with ME/CFS (NICE, 2021). Where appropriate, interviews were carried out over one session. However, participants could opt for multiple shorter sessions to respond to physical and cognitive needs and minimise potential harms related to PEM. Rest breaks were offered to participants at multiple points throughout the interviews.

Participants under the age of 18 had the right to have a trusted adult present during interviews, should they wish; this was used by one participant, Meredith. This followed BPS (2021a) ethical guidelines and common practice in research with adolescents with ME/CFS (e.g. Clery et al., 2022; Parslow et al., 2020). Accompanying adults were asked not to contribute their own data or perspectives, although they were allowed to support CYP with understanding questions or keeping track of the thoughts, feelings, and experiences that they wanted to express, provided this was a required reasonable adjustment. This was particularly useful due to symptoms of ME/CFS, such as brain fog. This followed practice adopted by Lewis (2022) to support the recording of audio diaries by CYP with ME/CFS and BPS

(2021a) ethical principles related to respecting participants' comfort, autonomy, preferences and needs.

3.6.7 The Process of Data Collection

Informed consent was obtained prior to interviews. As part of the virtual GEM protocol, participants were emailed a two-by-two A4-sized grid, without instructions, prior to interviews and asked to either print or draw it on plain paper in preparation for the interview.

Interviews began with an informal conversation to build rapport before recording. Once recording had commenced, an introduction ensured informed consent and confirmed reasonable adjustments. This was followed by the GEM activity, and then further questioning using the semi-structured interview schedule. Regular check-ins and opportunities for breaks were offered throughout the interviews. A debrief at the end explored participants' experiences of participating in the research and the requirement for any further signposting to support.

Interviews were conducted virtually, using the researcher's university Zoom account or telephonic communication, where both the researcher and participants joined from a private, quiet environment. In Zoom interviews, the interviewer used headphones and blurred their background. In the telephone interview, participants were informed that they would be called from a private number to ensure confidentiality regarding the researcher's personal contact details. At the start of the telephone interview, the researcher described their environment and ensured the participant was also in a comfortable, private environment.

Table 6 displays information regarding the length, mode of interview and reasonable adjustments within interviews. Interviews lasted between 66 and 95 minutes.

Table 6

Interview Information

Participant	Interview duration (mins)	Interview mode	Reasonable adjustments
Kiara	67	Zoom	Interview broken up into five sessions of up to 15 minutes and paced appropriately over the course of a month.
Jenny	70	Zoom	-
Florence	95	Zoom	Breaks
Freya	66	Zoom	Break
Lucy	77	Telephone	-
Meredith	74	Zoom	Trusted adult (mother) present to support with understanding questions and expressing thoughts due to brain fog.

3.6.8 Transcription

Interviews were video and audio recorded and transcribed using Zoom software. Recording and transcript files were downloaded onto the researcher's password-protected laptop and saved on OneDrive. The same procedure was followed for the telephone interview, where the researcher, with participant consent, used speakerphone to facilitate audio recording and transcription via Zoom.

Orthographic transcription was used to generate a complete verbatim record of spoken words from interviews (Braun & Clarke, 2013). Although Zoom created transcript files from the recording, these required editing and multiple checks against audio recordings. Each interview recording was replayed and transcribed against the autogenerated Zoom transcript, with multiple pauses and re-listenings. All identifying names or information were removed.

3.7 Data Analysis

Interview data was analysed using RTA to facilitate the identification of recurring themes and offer insight into patterns of meaning (Braun & Clarke, 2022). In line with suggested procedures for the GEM (Joffe & Elsey, 2014), analysis focused on interview transcripts rather than the contents of the grids themselves.

Braun and Clarke (2022) describe a six-phase process for data engagement, coding and theme development within RTA. Figure 11 displays how the process was followed in a recursive and iterative manner, with reflexivity at the core, considered at every phase through reflexive journalling and regular supervision. As such, although the phases are described one by one, the analysis involved forwards and backwards steps between phases.

Figure 11

Visual Representation of the Six-Phase RTA Process

Note. Based on Braun and Clarke (2022).

3.7.1 Phase 1: Familiarisation

The first phase of analysis involved a process of immersion, critical engagement, and initial note-making as thoughts related to the dataset arose. Transcription supported initial familiarisation, followed by immersion through reading and re-reading each transcript. As the researcher developed deep familiarity with the content of the dataset, notes were recorded to outline salient concepts and possible patterns. The researcher began to make sense of and critically engage with the data through questioning, critiquing, and imagining how things could be different (Braun & Clarke, 2022). At the end of this phase, an overall note related to the whole dataset was written to capture potential patterns of meaning and questions related to the data.

3.7.2 Phase 2: Coding

During the next phase, codes were assigned systematically to capture specific meanings within the dataset. Semantic and latent coding were utilised to understand participants' experiences at the surface level and through deeper exploration of the social, psychological, and contextual processes influencing them.

Coding followed an organic, iterative process refined over multiple rounds. Data was read in varying orders to disrupt a familiar flow and ensure an evenly coded dataset. Given the value placed on subjectivity within RTA, the use of a single coder, the researcher, was considered good practice (Braun & Clarke, 2022).

An inductive coding orientation was adopted to emphasise participants' lived experiences. However, it was acknowledged that pure induction would not be possible or desirable due to the important role of the researcher within analysis, positioned theoretically and as an 'insider-outsider' researcher (Braun & Clarke, 2022). At this stage, reflexive journalling was used to record the researcher's assumptions, decisions, thoughts, and feelings (Figure 12).

Figure 12

Reflexive Diary Extract 7

Reflecting on Codes Related to Age Influencing Power and Voice

As I reflect on the code ‘Age Influencing Power and Voice’, I notice how strongly this resonates with me, evoking an emotional response of frustration and disappointment with systemic inequities. I recognise that this is likely shaped by my prior knowledge of ME/CFS as a poorly understood and stigmatised condition, coupled with my interest in systemic theory which drives my attention towards considering broader systemic factors beyond the individual. Furthermore, in my applied practitioner role as a Trainee EP, prioritising the voice of the child is central to all of my work. These experiences expressed by CYP therefore conflict with my personal and professional values, amplifying my commitment to promoting the voices of those with lived experiences to promote person-centred care for CYP with ME/CFS.

NVivo, a qualitative data analysis software (QDAS), was utilised to support data organisation and coding efficiency. This is illustrated in Appendix M. The researcher acknowledged that NVivo’s implicit research values lend themselves towards realist research and speed and efficiency within analysis, conflicting with the deep engagement and time required for RTA (Braun & Clarke, 2013). Critical reflexivity ensured that these limitations did not drive the analytical process.

The researcher moved on from coding when, after going through all the data at least twice, code labels were judged to provide a sufficient summary of the diversity of meanings contained within the dataset (Braun & Clarke, 2022). Nevertheless, this phase was revisited multiple times to add, remove, broaden, and rename codes as part of the iterative analytical process.

3.7.3 Phase 3: Generating Initial Themes

At the third phase, candidate themes were developed by identifying shared patterns of meaning across the dataset. Miro, a free online whiteboard platform, was used to support with visually clustering codes, represented as virtual Post-Its, into broader patterns which shared core concepts. A number of provisional themes which told a story about the dataset were generated to address the RQs (see Appendix N). These were also influenced by knowledge and insights held by the researcher; reflexive journalling and supervision were crucial to reflect upon and record what the researcher brought to the analysis. Initial candidate themes were reworked several times using visual mapping on Miro to support the researcher in considering their relationships and exploring the scope of the developing analysis.

Given the time pressures of completing a thesis, at times, it was difficult to resist the temptation of becoming attached to early-developed themes in an attempt to get to the endpoint (see Figure 13). The researcher utilised imagery of a winding path to remember that “finding, losing, and finding your way again” (Braun & Clarke, 2022, p. 79) is encouraged within RTA and took a break from the analysis process when challenges with keeping open-minded arose.

Figure 13

Reflexive Diary Extract 8

Staying with Phase 3 of RTA

I find myself trying to navigate the tension between wanting to move on from phase 3 of RTA due to the pressures of thesis deadlines and feeling uncertain and unprepared to progress further. Whilst I was happy with my initial candidate themes yesterday, I now find myself doubting whether I have looked deeply enough underneath the surface, paying due to both semantic and latent meanings within my dataset.

As a committed practitioner, and a self-confessed perfectionist, I feel a sense of responsibility to my participants and the ME/CFS community to really squeeze every last drop out of what they generously shared with me in interviews, to really get to the crux of what school and support experiences are like for this group, what support is needed, and how we can move to drive change and promote positive experiences. I feel I'm putting a lot of pressure on myself to 'get it right' and not miss anything, even though I know that in RTA, there is no 'right' answer, just my interpretation. It's not like something is sitting there waiting to be found/emerge within the data, but actually it is my active engagement with the data that is necessary to generate meaningful and impactful findings. I'm hoping that by resisting the urge to move on just yet, and by actively engaging some more at this phase, I will further deepen my interpretation.

3.7.4 Phase 4: Developing and Reviewing Themes

At this stage, the researcher re-engaged with coded data extracts and the entire dataset to consider the goodness of fit of themes. The viability of themes and opportunities for improvements in pattern development were considered. Questions presented in Table 7 were utilised to support development and review.

At this stage, thematic mapping using Miro was employed again to visualise the overall story of the analysis (see Appendix O). The focus was then expanded by revisiting the entire dataset.

Table 7

Questions for Developing and Reviewing Themes

#	Question
1	“Can I identify boundaries of this theme?”
2	“Are there enough (meaningful) data to evidence this theme?”
3	“Are the data contained within each theme too diverse and wide-ranging?”
4	“Does this theme convey something important?”

Note. Questions from Braun and Clarke (2022, p. 99).

In acknowledgement of the researcher’s role within RTA, the relationship between themes, existing knowledge, practice within educational systems, and wider contextual factors were considered and reflected upon within supervision and a reflexive journal (Figure 14).

Figure 14

Reflexive Diary Extract 9

Are My Themes Distinct? A Hard Question When Thinking Systemically

Reviewing my themes, I often find myself deliberating about whether I can identify their boundaries. Whilst I can delineate boundaries between them, I cannot help but notice how themes related to systemic issues and relationships are pervasive in influencing all other themes. For example, stigma within society seeps into feelings of invisibility and neglect, social isolation, and identity challenges.

Given the systemic approach adopted within this research, emphasising the interconnected nature of CYP’s systems that shape experiences (Bronfenbrenner, 1979), and my own interest in systemic theory highlighting circular causality and feedback loops (Bateson, 1972), it is perhaps unsurprising that I find myself drawing links between aspects of experience. Use of research supervision to reflect on this and pausing to explicitly note the focus and boundaries of each theme has been crucial in supporting me to develop confidence that my themes are clearly and distinctly defined.

The reflexivity afforded by RTA has enabled me to acknowledge my role in foregrounding relationships and systemic issues surrounding ME/CFS. Given that much of the evidence on ME/CFS is saturated by more individual-focused medical literature, I am proud to contribute this alternative focus within my research.

3.7.5 Phase 5: Refining, Defining and Naming Themes

Themes were then refined by ensuring they were each built around a strong core concept and clearly demarcated. Themes were defined in a brief synopsis and named, avoiding one-word labels to ensure that the pattern of meaning was evident (Braun & Clarke, 2022). A final thematic map was produced using Miro to visualise how themes and subthemes contributed to the overall story of the analysis (Appendix P).

At this point, themes were reworked if the following conditions, suggested by Braun and Clarke (2022, p. 111), could not be clearly stated:

- “What the theme is about (central organising concept).
- What the boundary of the theme is.
- What is unique and specific to each theme.
- What each theme contributes to the overall analysis.”

3.7.6 Phase 6: Writing Up

Braun and Clarke (2022) consider writing to be a key component of the analytic process. Informal writing commenced from the very start of the process in the form of a reflexive journal. The formal writing process involved refining analytic work and careful consideration of how to tell the analytic story in a way which engaged the reader and demonstrated validity and quality of the analysis.

Given that this thesis has a public audience, including academic examiners, the author decided to write in a style that conformed with conventions and expectations appropriate for an academic thesis. Third-person was, therefore, applied within the write-up of this thesis, despite Braun and Clarke's (2022) preference for first-person language. Reflexive diary entries were written in first-person to support self-awareness and ownership regarding the researcher's role within the research (Trainor & Bundon, 2021) and to keep the researcher visible to promote transparency.

3.7.7 Interpretation and Reflexivity

The analysis was primarily descriptive, staying close to participants' sense-making regarding their school experiences (Braun & Clarke, 2022). Nevertheless, this was balanced with an interpretative approach that identified patterns and examined their meaning and implications, particularly within the wider societal context following evidence emphasising its impact in ME/CFS (DHSC, 2024). The critical realist ontology and contextualist epistemology adopted within this research supported the exploration of these underlying mechanisms and contextual factors. Interpretation was embedded throughout the analytic process (Braun & Clarke, 2022).

Although anchored to the RQs, interpretation was inevitably influenced by the researcher's own context, identity, psychology, values, assumptions, experience of ME/CFS, and prior knowledge. Given this and the instrumental role of subjectivity within RTA, reflexivity was essential to support the researcher in immersing themself within the data, whilst maintaining sufficient distance to critically reflect upon their role in shaping meaning-making. A reflexive journal was kept to record how meaning was constructed, considering what scholarly knowledge, theory, ideology, context, and other factors influenced this (Braun & Clarke, 2022). Supervision also supported reflection upon influences, particularly when these were less easily accessible to the researcher. The following questions were utilised to ensure defensibility in interpretation (Braun & Clarke, 2022, p. 201):

- "Are there good grounds for what I'm claiming?"
- "Am I ignoring some inconvenient "truths"?"

3.8 Ethical Considerations

Ethical approval for this research was granted by the Tavistock and Portman NHS Foundation Trust's Research and Ethics Committee in May 2024 (Appendix G). Further ethical approval was granted in July 2024, following an application to expand the reasonable adjustments available for participants, including telephone interviews and splitting the interview over more sessions.

Research ethics were considered throughout the entire research process to ensure that principles of the BPS (2021a) Code of Human Research Ethics and the BPS (2021b) ethics guidelines for internet-mediated research were adhered to. This section will discuss ethical considerations within the research.

3.8.1 Respect for the Autonomy, Privacy and Dignity of Individuals, Groups and Communities

This study was motivated by a wish to respect the insights and experiences of CYP with lived experience of ME/CFS within secondary school. To ensure respect for the autonomy, privacy, and dignity of participants and the wider ME/CFS community, ethical considerations were made regarding valid consent, respect for autonomy, confidentiality and anonymity, and dignity.

3.8.1.1 Valid Consent and Right to Withdraw. Following NICE guidance for supporting CYP with ME/CFS (2021) and to ensure informed consent, information about the research was shared via interactive formats, including a written information sheet (Appendix H), an easy-read version with pictures (Appendix I), and a one-to-one discussion at the start of the interview. This detailed the research purpose, process, and participants' right to withdraw until 3 weeks after their interview. Sufficient time was provided for participants to read and consider the information; this was particularly important for participants with ME/CFS due to brain fog and the need for pacing.

A written consent form (Appendix J) confirmed informed consent for participation, including the use of video and audio recording. Since participants were aged over 16, consent was sought directly from them in adherence with the principles of Gillick competence (BPS, 2021a). If trusted adults were requested to be present for interviews, they were also required to follow informed consent procedures and complete a trusted adult consent form (Appendix Q).

3.8.1.2 Respect for Autonomy. During interviews, the researcher respected the autonomy of participants by remaining sensitive to possible non-verbal signs of discomfort and checking in regarding their consent to continue. Participants voluntarily opted to participate in the study and were reminded that they could share as much or as little as they felt comfortable with.

3.8.1.3 Confidentiality and Anonymity. Interviews were conducted remotely, with participants and the researcher joining from a private, confidential space. The privacy of participants was protected using pseudonyms and de-identification of the data. However, due to the small sample size, there remained a risk that participants may be identifiable; this was made explicit within participant information sheets. Safeguarding responsibilities and the limits to confidentiality were clearly outlined within the information and consent sheets and at the start of each interview in case of any disclosures raising safeguarding concerns. Trusted adults were also asked to respect confidentiality by not sharing information discussed within interviews with anyone else.

In line with BPS (2021b) ethical guidelines for internet-mediated research, the researcher developed a data management plan to support data security. Practice followed the Tavistock and Portman NHS Foundation Trust's Data Protection and Handling policies and complied with the Data Protection Act 2018 .

3.8.1.4 Dignity. To respect the dignity of participants, careful consideration was given to the language used within interviews. Language can reflect and promote oppressive ideologies (Galvin, 2003), and terminology is a particularly prominent debate within the ME/CFS community (Petrison, 2015; Verrillo, 2015; Wotherspoon, 2021). In recognition of this, participants were consulted on their preferred language descriptors. Five participants expressed a preference for 'ME', while one preferred 'CFS'. As such, this thesis respects the identities and preferences expressed by participants in its use of language. When referring to the participant group, 'ME/CFS' is used, in accordance with NICE (2021) guidelines, as this encapsulates all participants' preferences.

3.8.2 Scientific Integrity

Scientific integrity is a crucial principle underpinning ethical research (BPS, 2021a). This requires that research methodologies ensure quality in relation to research design and mitigation of potential risks of harm, integrity, and valuable contribution. The researcher drew upon Yardley's (2000) principles for quality qualitative research. This section will reflect upon the extent to which this research ensured sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance.

3.8.2.1 Sensitivity to Context. Yardley (2000) highlights the importance of sensitivity to context. This study established the sociocultural context of ME/CFS and educational support within Chapter 1, exploring the current and historical context, policies and legislation, and relevant theoretical frameworks. Chapter 2 reviewed existing research on ME/CFS in education, shaping the RQs, design, and interpretation. Contextually situating this research required particular attention to the misinformation and attitudes surrounding ME/CFS.

The social context of the relationship between the researcher and participants was crucially considered. A semi-structured interview using the GEM and open-ended questions was chosen to encourage participants to speak freely about what was important to them, rather than being constrained by the researcher's preconceptions (Wilkinson et al., 2004). However, the researcher acknowledged the power imbalance and their role in shaping the research process and what participants shared through their actions, characteristics, and context (Mishler, 1986; Ochs, 1997; Pomerantz & Fehr, 1997). The researcher chose not to disclose their lived experience of ME/CFS to participants; whilst this could facilitate rapport and address power dynamics within interviews, potential impacts upon emphasising comparison and shifting focus away from centring CYP's own lived experiences (Abell et al., 2006) led the researcher to choose not to voice this aspect of their identity. Reflexivity regarding the role of this relationship was supported through interview debriefs with the research supervisor (Brantlinger et al., 2005) and reflexive journalling.

3.8.2.2 Commitment and Rigour. Commitment requires prolonged engagement with the subject, development of skills and competence in the research methods, and immersion in the data (Yardley, 2000). Lived experience of ME/CFS during childhood, discussions with colleagues about professional contact with ME/CFS in school-aged CYP, and extensive reading of both published literature and online content supported extensive in-depth engagement with the topic.

Rigour necessitates consideration of the completeness of data collection and analysis (Yardley, 2000). Although small, the sample size was considered adequate based on the scale of the project and its aims, as described previously. The researcher read extensively about applied research methods and quality RTA to develop methodological competence. Immersion and repeated engagement with the dataset, coupled with research supervision, supported in-depth, thoughtful, and empathic exploration and interpretation of the data. Braun and Clarke (2022) encourage an iterative approach to RTA and thus continued reflection and reviewing of themes supported rigour within analysis.

3.8.2.3 Coherence and Transparency. To ensure coherence (Yardley, 2024), the researcher established a solid grounding in the theoretical and philosophical orientation of this research and considered the goodness of fit of this with the methods and RTA approach within this chapter. Justification was provided for the methods employed, and congruence was ensured. For example, given the interpretative nature of RTA, a single coder was used within this study in recognition of the desirable role of the researcher and subjectivity within RTA (Braun & Clarke, 2022).

Transparency was facilitated by providing detailed descriptions of the methods and analytical process within this chapter (Yardley, 2000). Presentation of quotations, illustrative thematic maps, and reflexive journal excerpts supported transparency in the presentation of analysis. The researcher explicitly reflected upon their identity and motivations for the research, discussing the role of their insider-outsider status. Reflexive journalling logged how the researcher’s assumptions, intentions, and actions may have affected the products of the research, as well as the likely influence of other external pressures, such as the nature of this research as part of a doctoral thesis.

3.8.2.4 Impact and Importance. Careful consideration was given to the potential for this research to make a difference, ensuring impact and importance. At the time of writing, there was a significant effort to raise awareness and understanding about ME/CFS at a national level, following widespread issues related to understanding and stigma (DHSC, 2024). Qualitative exploration of lived experiences intended to elucidate sociocultural processes influencing what is already known about lower levels of school functioning and greater psychosocial difficulties in CYP with ME/CFS from quantitative studies (Ali et al., 2019; Knight et al., 2018). This research, therefore, aimed to contribute to a change in the way education professionals think about ME/CFS and the support CYP need to have positive school experiences. Furthermore, practical implications regarding the inclusion needs of CYP with ME/CFS were intended to be drawn, which would have immediate relevance for school staff, EPs, families, policy makers, and the general community.

3.8.2.5 Quality in RTA. Since the introduction of TA (Braun & Clarke, 2006), Braun and Clarke have written extensively about good practice and problems in TA research and refined RTA methodology (e.g. Braun & Clarke, 2023, 2024). Therefore, in addition to Yardley's principles, the researcher considered recommendations for ensuring quality in RTA research (Braun & Clarke, 2023), accompanied by thoughtful engagement and understanding.

Immersion, creativity, thoughtfulness, insight and patience are key quality indicators in qualitative research and RTA (Braun & Clarke, 2022; Gough & Lyons, 2016). To ensure quality, reflexive journalling supported thoughtful engagement, supervision provided opportunities for thoughtful, insightful discussion related to interpretation and themes, and reading of published examples developed competence and supported the researcher's creative use of RTA. Given the time pressures of completing a thesis, the researcher employed early planning to demarcate sufficient time for immersion and thoughtful and considered analysis, facilitating the ‘slow wheel of interpretation’ (Braun & Clarke, 2021b).

3.8.3 Social Responsibility

Ethical codes highlight the social responsibility of psychologist researchers (BPS, 2021a). The researcher took measures to ensure social value while protecting people from harm in the design, conducting, and writing of the research.

As ME/CFS is often overlooked and stigmatised (Anderson et al., 2012), this research sought to bring social value by exploring lived experiences in the hope that educational professionals can learn from this to promote inclusive practice and improve experiences for CYP affected by the condition. This followed gaps in the evidence base, highlighted in Chapter 2.

Representational ethics refers to the responsibility to accurately, respectfully and fairly portray participants and their experiences in research findings (Haarlammert et al., 2017). This poses a significant ethical dilemma within qualitative research due to the risk of misrepresentation or harm (Swauger, 2011). To mitigate this, the researcher carefully considered interpretative influences, recognising the transformative nature of analysis (Willig, 2017). The researcher intended to challenge ideas related to the negative stereotypes, biases, and attitudes towards ME/CFS (Hughes et al., 2023) within the write-up. As a partial insider, the researcher reflexively drew upon their lived experience to support deeper insights, while ensuring fair representation (Haarlammert et al., 2017).

To address risks related to representational ethics, informed consent ensured that participants were aware of the research purpose and intended use, with opportunities provided to ask questions. Some gatekeepers and individuals initially expressed concerns about this, following previous psychological research, which had harmful effects on the understanding and treatment of patients with ME/CFS (White et al., 2011; Wilshire et al., 2018). The researcher clarified their position as viewing ME/CFS as a neurological condition and emphasised that the study aimed to improve knowledge amongst education professionals and support within schools.

3.8.4 Maximising Benefit and Minimising Harm

The researcher acknowledged their responsibility to maximise benefits whilst ensuring that CYP did not suffer harm as a result of their participation in the research (Morrow & Richards, 1996). The study aimed to reap benefits by empowering participants' voices, drawing attention to their lived experiences and the support needs of CYP with ME/CFS in education. This was particularly important given that this participant group has been subjected to epistemic injustice, experiencing disbelief, marginalisation, and unethical treatment (Blease et al., 2017). Further, the research was intended to be a positive experience, following previous research highlighting that people with ME/CFS have valued participation in research for supporting them to make sense of their illness experiences (Lacerda et al., 2019).

The research involved recollecting potentially distressing memories about difficult experiences. To minimise potential harm associated with the emotive interview content, interview questions were phrased sensitively, and the interviewer acted as an empathic listener (Brounéus, 2011). Participants were reminded that they could pause or stop the interview at any time. The researcher checked in regarding participants' wellbeing throughout interviews and a debrief form (Appendix R) signposted participants to charities and organisations that could provide support and advice.

Given the nature of ME/CFS symptoms, the researcher followed NICE guidelines for supporting CYP with ME/CFS (2021) to minimise harms. Flexibility was offered to provide reasonable adjustments which met participants' individual needs. Regular check-ins were built into the interview to review exertion levels, with the option to take a break or stop interviews as needed.

In accordance with BPS (2021a) ethical guidance and previous research with adolescents with ME/CFS (e.g. Clery et al., 2022; Parslow et al., 2020), participants under the age of 18 had the right to have a trusted adult present to support their participation and safeguarding, if they wished.

3.9 Chapter Summary

This chapter described the research purpose and questions guiding the current study. The research orientation and researcher positionality guided choices to utilise RTA as a qualitative approach to analyse virtual interview data. Participant recruitment and characteristics were described, followed by data collection processes and the six phases of RTA that were followed. Attention was given to ethical considerations within the research, including how quality and scientific integrity were ensured. Reflexivity was central throughout the research process and is demonstrated through reflexive diary extracts included within this chapter.

4. Analysis

4.1 Chapter Overview

This chapter will outline key findings of this research. In keeping with RTA (Braun & Clarke, 2022), themes and subthemes generated by the researcher will be defined, and the central organising concept of each theme explored to tell the analytic narrative in response to the RQs. Data extracts will be used illustratively and analytically to support the analytic narrative and to offer evidence for the process of theme generation. The term CYP will be used throughout this chapter to describe the participants of this study who had ME/CFS.

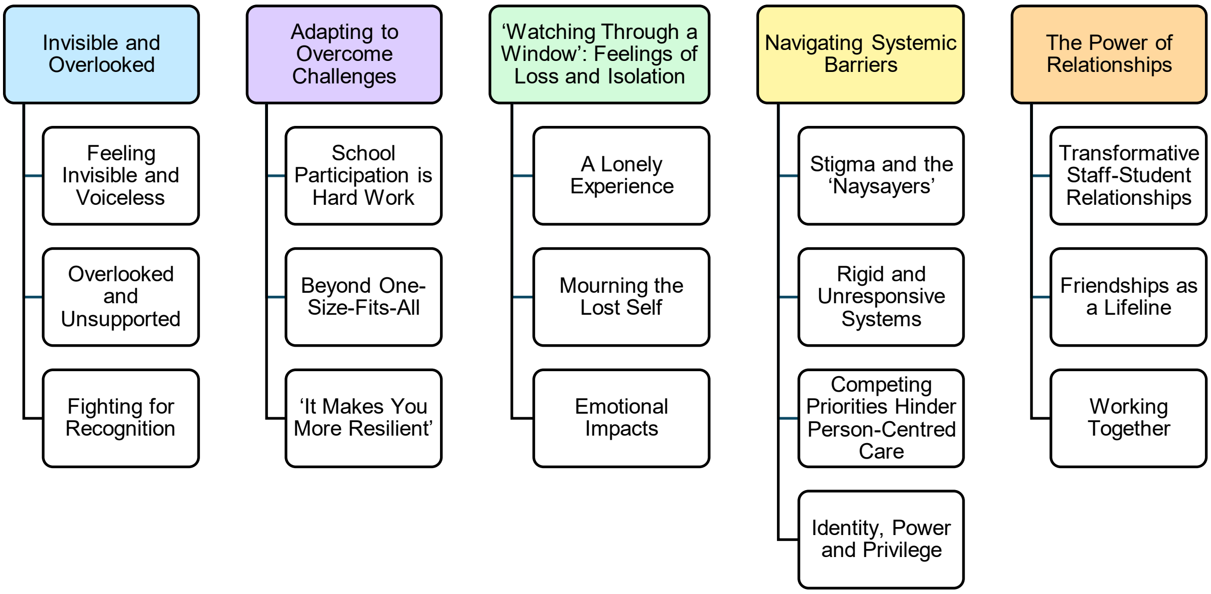
4.2 Thematic Structure

Five themes were generated by the researcher. While subthemes are only to be used if needed (Braun & Clarke, 2022), sixteen were judged necessary in this research to capture important facets of each theme's central organising concept. An overview of the thematic structure, including themes and subthemes, is presented in Figure 15.

Both RQs were analysed together due to the interconnected nature of school experiences and support. These were reciprocally influential; school experiences and challenges gave rise to support needs, while the quality and nature of support shaped how school was experienced. This integrated approach facilitated a holistic understanding and avoided artificially isolating aspects of experience. This chapter therefore considers both RQs in unity. Implications for each individual RQ will be considered in the summary and discussion.

Figure 15

Overview of Themes and Subthemes



4.3 Theme 1: Invisible and Overlooked

This theme explores the idea that CYP widely felt unseen, unheard, and unsupported in school systems. It illuminates the various ways in which invisibility manifests within school experiences, from struggles not being observable, to feeling forgotten by staff and having to constantly self-advocate.

4.3.1 Subtheme: Feeling Invisible and Voiceless

This subtheme captures how CYP experienced a profound and multifaceted sense of invisibility within school in relation to their needs, presence, and voice in decision making.

The invisibility of ME/CFS meant that CYP's struggles were often unobservable to others, as Kiara described: "When something's invisible, sometimes people don’t realise how bad it is.” This contributed to a lack of recognition, understanding, support, and a sense of invalidation from school staff and peers, as described by Lucy: “Being ill, and it being an invisible illness, no one's going to really see what the problem is, and it looks like I'm either lying or I'm just really lazy.”

Feelings of invisibility also manifested in a relational sense. Reduced school and social participation led to CYP feeling forgotten socially, academically, and within school systems. For many CYP, this impacted the extent to which they felt valued and important to others, experiencing a sense of erasure associated with their absence: “If you're not in visual sight of a person, then you don't exist really” (Lucy).

This contributed to CYP feeling as though both they and their needs were forgotten within the classroom. Kiara described that “in the individual classes with teachers, especially that I didn't see very often, they would quite often forget or not really know [about my needs]”. This limited CYP’s access to support and the curriculum:

> They would either forget to start the meeting entirely and I would be like left on the other end of the computer […] Or […] put me against a blank wall and I'd have to, like, try and listen to like what was going on. And like they'd be writing on the whiteboard, and I couldn't see what they were writing. (Jenny)

For Jenny, virtual participation became symbolic of her invisible presence, resulting in a sense of exclusion and reduced access to learning.

Crucially, invisibility also extended to voice. Florence described that school staff “wouldn't listen”, feeling “like you're like banging your head against a brick wall” in attempting to advocate for her needs. A power imbalance between CYP and ‘grown-ups’ led to persistent struggles to have their voices heard, leaving CYP widely feeling dismissed or infantilised:

> The constant battle of 'I'm telling you, I feel this way', and every other grown up is telling me 'No, you don't. That's not how you feel. That's not how you should be feeling.' And being ignored in me standing up for myself. (Lucy)

This demonstrated how CYP often felt overshadowed by adult voices, reducing their sense of agency and autonomy. Florence described this experience as feeling “like I was piggy in the middle”, while Lucy explained that she was “dragged pillar to post with my mum being in charge”. These metaphors convey a sense that, despite being at the centre of discussions about their educational support, decision-making occurred over their heads with no power afforded to their voices or views.

4.3.2 Subtheme: Overlooked and Unsupported

This subtheme captures common experiences of feeling overlooked and unsupported. Despite feeling as though they were not asking much of school staff, CYP often felt abandoned and left to struggle without quality support in school. This not only created practical barriers within education, but also placed an emotional burden upon CYP.

A recurring sentiment within CYP's accounts was that no one cared or prioritised their needs. This lack of felt care resulted, not only in limited practical support, but also in an emotional sense of feeling overlooked and undervalued, conveyed by Freya, who described how teachers "kind of just didn't support me or didn't seem interested in, um, well, supporting me and stuff".

CYP described that their personal circumstances, social, and emotional needs were particularly overlooked within school. For Florence, being a young carer was a "big thing in [her] life" but "school didn't recognise that would have come into it", for example, not recognising that "I'm not going to get like homework in on time because I've I've got chronic illness and I'm looking after someone else". Lucy also explained how "being autistic played massively into having ME […] And it, again, wasn't paid attention to in school". She also expressed, "no one asked how I actually felt about having ME, no one asked how my friends were about it, no one... no one actually cared I don't think."

The failure to acknowledge the full complexity of CYP's needs and holistic experiences resulted in CYP widely feeling unsupported "most of the time" (Lucy). Thus, Florence felt she "had to kind of jumble along with what I had", left to navigate the struggles within education alone.

Where support was offered, inconsistency led to further uncertainty. Freya, for example, had an exit pass to use in lessons. However, inconsistent responsiveness to such approaches among school staff hindered her confidence in using this when she needed to: "When I was not feeling well, then I had the anxiety of not feeling well and whether I could, you know, leave if I needed to". This negated experiences of support and exacerbated anxieties related to managing within the school environment.

Despite this, CYP's requests were often modest. Frequent use of the word 'just' within CYP's accounts highlights the simplicity of their needs, which were widely overlooked and unsupported. For example, Kiara described how "it does make a lot of difference when someone just understands", commenting that she didn't "necessarily need all of these like... concessions, I just need someone to understand". Similarly, Freya wished school staff would "just simply [ask] us what we need […] or just [take] that bit of extra time to explain something".

4.3.3 Subtheme: Fighting for Recognition

This subtheme captures the burden placed on CYP and their families to self-advocate and fight for recognition, given the invisibility and overlooked nature of their needs, and the subsequent impacts of this.

Widespread across experiences, the onus was placed upon CYP to communicate their needs to school staff: "The school said it's up to me to communicate to teachers" (Meredith). Jenny described how she "was the one who had to go up to the teacher and be like, 'Excuse me, miss. I can't do that'", indicating a lack of responsibility from school staff to proactively monitor and respond to needs.

Being unwell heightened challenges with self-advocacy. Having to continuously self-monitor and alert staff to their needs added cognitive strain, depleting energy and heightening emotional stress as “the last thing you want to have to do when you don't feel well is think yourself of everything that you might need” (Kiara). CYP conveyed a sense that it should not be their responsibility to manage the arrangement of their support, but often had no alternative:

> There's a lot of energy spent like on me trying to trying to get my education […] I have limited energy anyway so, you know, what energy I do have should be spent on learning, not trying to chase up the learning. (Jenny)

In some cases, staff alleviated this fight by recognising CYP’s needs and helping them to manage these within school, which was experienced positively:

> It was just nice to have someone sit down and go 'You're not in a fit state to do this, you know. You don't have to push yourself at all, like you can go home, rest, recover or come back when you feel better.' (Florence)

Florence’s account indicates that staff advocacy was pivotal in recognising and responding to her body’s limits. Without this, the fight for support may hinder responsiveness to need.

Given widespread self-advocacy challenges, parental advocacy was crucial. However, navigating a poorly understood condition and unfamiliar, complex educational support systems complicated their fight for recognition and support. Freya expressed, “I didn't know what I needed. I didn't know what I wanted. Neither did my mum. It was all very new to us.” Jenny similarly noted, “We didn't really know any better, so we kind of just went along with it.”

Resistance from schools to acknowledge and respond to needs further exacerbated challenges with self-advocacy. CYP frequently used language related to a fight or battle to describe this experience: Lucy described “the constant battle of 'I'm telling you, I feel this way'”, while Freya described that “it was a bit of a battle” and her mum “had to kind of fight” to arrange support in school.

4.4 Theme 2: Adapting to Overcome Challenges

This theme explores the challenges CYP experienced in school participation and learning, whilst also capturing a hopeful outlook on how these can be overcome through flexible, tailored, and individualised school support and the resilience demonstrated by CYP.

4.4.1 Subtheme: School Participation is Hard Work

School participation and engagement in learning was hard work for all CYP. This subtheme captures the breadth and severity of the challenges of school participation whilst living with ME/CFS, relating to physical, sensory, cognition and learning needs.

Physical symptoms of ME/CFS were an unavoidable challenge which significantly impacted CYP’s school attendance. Florence described, “The number one hurdle of living with ME at school is the fact it's being able to attend school,” adding, “My health just wasn't allowing me to attend like full time like everyone else”.

A taken-for-granted privilege for most, Freya also described how she “was so poorly” that “even if I wanted to be at school, I couldn't because […] I just felt too ill”. This resulted in prolonged school absences and remote learning for many CYP.

Those who were able to continue attending on a part-time basis also struggled with the hard physical work required, even to prepare themselves to set foot within the school gates:

> Getting to school was like a challenge in itself like. You know, that was hard work, you know, getting ready for school. By the time I'd done that... I'd sometimes feel like I've done this already done like loads of work, just trying to get there. (Kiara)

The challenges continued once in school, as despite physical presence, fatigue made active participation challenging. Jenny described PEM arising from efforts in school: “You pay for things, you pay for what you're doing and like you have a pocket of energy, and if you use it, then you can't do anything else.” Therefore, careful prioritisation of energy expenditure in school was important. Freya shared that she “was kind of in the lesson just to sit there and listen and observe rather than participate”, as “actually having to contribute and interact” was difficult due to fatigue.

Challenges with the sensory aspects of the environment, specifically noise and light sensitivity, often contributed to feelings of overwhelm and difficulties managing within school: “The lights in the classroom are always white, horrible lights and the amount of people going through from classroom was just hellish” (Lucy).

This was particularly challenging for CYP with neurodevelopmental conditions, as sensory sensitivities associated with both diagnoses compounded, with Freya reflecting, “I think I struggled with that more or as well as with the autism as well.”

Beyond physical and sensory challenges, the hard work extended to learning due to the cognitive impacts of ME/CFS. Difficulties with brain fog, processing, attention, and memory significantly affected academic functioning. Kiara explained, “I get a lot of brain fog, so I would I don't know, be a paragraph into it and not be able to concentrate or think straight.” Lucy described how this impacted exams, saying she “mentally couldn't revise enough for all of them” and “couldn't retain the information [she] needed to”. Reflecting more extensively on the cognitive impacts, Lucy noted:

> I felt like I've been put on a massive sort of like a mental reset of all my knowledge, and that something I'd read 30 seconds ago would not have stayed in my brain […] my brain turned into a massive sieve. (Lucy)

This posed CYP with a trade-off, where “you have to work harder to catch up, even though you kind of need to work less hard for the other parts of having ME” (Kiara). Thus, striving to keep up academically came at a health cost. The rigid demands of schooling and assessments conflicted with the fluctuating symptoms and need for flexibility in managing ME/CFS, forcing CYP into an impossible balancing act. Florence described how this “either meant you had to give way to part of the curriculum or you had to try and overwork yourself”, which conflicted with “the number one thing you don't do with ME is over exert yourself”.

4.4.2 Subtheme: Beyond One-Size-Fits-All

This subtheme captures the important role of flexibility and responsive, tailored adaptations in supporting CYP's holistic needs in secondary school, beyond the one-size-fits-all approach sometimes experienced. Flexibility required schools to proactively adapt approaches to promote genuine inclusion in the learning environment.

Physical accommodations, such as designated rest spaces and access to inclusion rooms, provided valuable respite in school for many CYP. Florence described how she had access to "a rest room" which she "could go into and take a break", a "time out" card, and "the canteen skip queue pass". Freya valued the inclusion room as "it meant that [she] was able to still be at [her] school without actually being at school" when she was feeling unwell, with reduced demands in this environment.

CYP highlighted the importance of minimising cognitive overload and conserving energy in lessons through a variety of adaptations and in-class support. Florence described the value of "having someone to take those notes, to relay that information back to me if I didn't understand it, phrase it differently, or retain it for another time". When available, such support was highly valued. However, it was often more difficult to secure than physical accommodations; this suggested a hierarchy of support, where schools were often more responsive to visible, practical support needs than to the nuanced, individualised needs unique to ME/CFS. In the absence of ideal provision, CYP described what effective support could look like. For Meredith, this included "shorter lessons", a "5 minute break for a recap in the middle", and a "15 minute break in between lessons".

In responding to SEND, some CYP felt that schools applied a one-size-fits-all approach, which was more geared to common needs, like neurodiversity, but lacked flexibility to respond to the unique and fluctuating needs of ME/CFS.

> A lot of SEND like processes and like SENCOs [Special Educational Needs Co-ordinators] and all of that, it's all geared up towards people with like neurodevelopmental, uh, like disabilities and stuff like that, and not really geared up to people with, say for example ME, who need different accommodations from the norm. (Florence)

Given this, Florence described the need for creativity and flexibility when tailoring adaptations for CYP with ME/CFS.

> Think outside the box in terms of adaptations as well, like not just stick to the prescribed stuff that I've only been like told about or think would help everyone in SEND, like see if I could tailor that to specific circumstances […] one size definitely doesn’t fit all. (Florence)

This also pertains to exams, which were a prominent part of CYP’s secondary experiences. The structures surrounding exam arrangements supported CYP in accessing adaptations, which were valued by some. For example, Meredith “did the exams at home, and with the exam invigilator there, and the rest break included a conversation with the invigilator that had nothing to do with the exam and that helped [her] an awful lot”. However, exam arrangements were not always responsive to individual needs:

> A lot of the accommodations were put in place, but like, not for an illness like ME. You know, I was allowed things like extra time, but that didn't really, although it helped my brain fog and things like that, it it didn't help my energy limitations. Obviously, doing more is worse. (Jenny)

An element of flexibility that was widely demonstrated in school approaches involved reducing the demands placed on CYP in education, such as through reduced timetables, leaving lessons, or dropping subjects. For Meredith, “eventually [school] were like ‘You come in when you want, you can come and go and whatever.’” Freya similarly experienced reduced pressures:

> I could leave lessons if I needed to. I didn't need to actually be in school. […] They weren't pressuring me about that […] if I couldn't do a piece of work or, you know, homework, then I wouldn't be told off. (Freya)

However, whilst facilitating flexible access to support, these approaches relied on CYP removing themselves from the learning environment. Schools were less responsive in adapting the environment, teaching approaches, or curriculum delivery to promote genuine inclusion within the learning environment.

Whilst some welcomed the relief of pressure from school, accommodations felt like a compromise rather than true and equitable inclusion for many others. Kiara expressed, “I shouldn't have to drop a subject or do different subjects to other people. I should still be able to do the same amount of subjects or whatever I want, just in a different way.” This tension reveals a passive model of inclusion, where schools were willing to allow flexibility for CYP but rarely adapted their structures, curriculum delivery, or teaching approaches flexibly in response to diverse learning needs.

4.4.3 Subtheme: 'It Makes You More Resilient'

This subtheme captures the resilience demonstrated by CYP in navigating secondary school with ME/CFS, despite the significant challenges. CYP showed determination and strength by continuing to work hard, seeking the positives in their situation, and reflecting on personal growth throughout their accounts.

Although school functioning was often challenging, CYP predominantly remained motivated and committed to education, demonstrating a strong sense of perseverance:

> I think it's like being determined, like even though it might be hard, harder or, you know, like it might, you might struggle to do certain things and stuff if you wanna do it, you should keep doing it. (Kiara)

Rather than passively accepting their limitations, CYP often made active efforts to adapt and prioritise doing what was important to them. For example, Meredith described her strategy for managing her GCSEs: “I decided what I was able to do and what my brain wasn't able to cope with,” prioritising her studies accordingly. A sense of personal agency was conveyed in CYP shaping their academic experiences, demonstrated by Florence’s positive focus on what she could do: “I might not be well enough to attend the physical place, but I can still learn despite not being there.”

For some, overcoming these challenges led to a sense of pride and accomplishment, reinforcing the idea that success felt particularly significant given the odds stacked against them. For Jenny, managing to “do my GCSEs, or at least five of them” was an achievement she’s “still quite proud of because there was a time where I didn't think I'd be able to do any”. CYP redefining their sense of success was crucial in supporting this.

Experiences of adversity even contributed to personal growth and resilience-building. For Kiara, she felt “it makes you more resilient” as “you have to, you know, like keep picking yourself back up when sometimes it can knock you down quite a lot and make you quite ill”. Some CYP described shifting their mindsets and cultivating inner strength and self-belief as they navigated the challenges in their school experiences:

> I actually had to really change my mindset from very despairing being like, oh, this is my entire life, to sort of being like I need to to sort of get a grip and and focus on the future more than just what was happening now. (Lucy)

A narrative of growth was prominent within many CYP’s accounts, indicating some positive experiences despite the significant challenges faced. Many CYP actively sought out the silver linings, reframing their struggles as opportunities for personal growth:

> It taught me to be resilient and to try and find different ways of working around stuff. And I've gained some really useful like life skills and stuff from being sick and having the opportunity to figure out what works for me during that time. (Florence)

This mindset of seeking positives was evident in many CYP’s accounts, where gratitude was frequently expressed for the support received, despite it being limited. For example, both Freya and Meredith referred to feeling lucky: “I was very lucky that I could have that support” (Freya) and “…I was fairly lucky in that sense” (Meredith). This reflection highlights a paradox, as despite often feeling unsupported, CYP sought out experiences, no matter how small, to feel grateful for. Gratitude may have served as a psychological survival strategy to promote resilience in the face of challenge by positively reframing their difficult and disappointing experiences.

4.5 Theme 3: ‘Watching Through a Window’: Feelings of Loss and Isolation

This theme explores the personal and relational losses faced by CYP in school, impacting their sense of self, social belonging, and emotional wellbeing. They often feel as though they are ‘watching through a window’, isolated and shut out as their peers enjoy the experiences that they had hoped for but missed due to their illness.

4.5.1 Subtheme: A Lonely Experience

Social isolation and exclusion were defining and painful aspects of most CYP's experiences with ME/CFS during secondary school. This subtheme explores how ME/CFS restricted their social participation, with significant effects on their social connections with peers and school life. This led to experiences of feeling left behind, loneliness, diminished belonging, and self-worth. Experiences of social exclusion further exacerbated challenges.

A tension between the desire for connection and physical limitations imposed by ME/CFS created a difficult trade-off for CYP. Many longed to maintain friendships and social lives but found that the sheer effort required for this came at an unsustainable cost to their health, as "socialising with people takes a lot of energy" (Jenny). Therefore, "to be able to go to school and do or just do school work and stuff at home", Kiara "had to sacrifice doing other [social] stuff."

When ME/CFS restricted school attendance, peer relationships often suffered. CYP widely described how friendships were often contingent on their presence within school, as Lucy described, "friendship relies on you being in school Monday to Friday all year round". When attendance reduced, many found that their friendships broke down. For Florence, this meant that she went "from having a huge group of friends to literally no one, because of the hours that [she] was in school".

Reflecting on this experience, Lucy commented, "I guess the friendships were that fickle in, well, if you're not in school, we don't need to be your friend I guess." Her use of the word 'fickle' conveys a sense of fragility surrounding friendships at this age, and the sentiment that it felt as though friends could not be relied upon. This limited the emotional depth achieved within peer relationships. Even Meredith, who was able to maintain some friendships, reflected that “we didn't get very personal” in many of these.

Consequently, most CYP felt socially isolated and distant from their peers. As their friends’ lives continued, they drifted apart, often leaving CYP feeling unnoticed and forgotten. Florence described how “gradually friends just started dropping off. Like they'd kind of move on and kind of forget about you”. A painful sense of abandonment was conveyed, with CYP often expressing limited control over this loss. Jenny described feeling like she was “clinging on to them. And they were like, moving further away. [She] was like, 'No, don't forget about me'”.

Isolation experiences also impacted CYP’s self-worth and trust in relationships. For Florence, her “self-esteem and self-image and a lot of other related areas […] really took a huge hit”. Some CYP interpreted the implicit message related to losing friends as indicating that their value was tied to social availability and presence and that they were not actually important to significant others:

> I sort of learned very quickly that I don't mean much to people if I can't physically be there, and and that's that's my school, that's friends, that's even my family. That if I can't physically text people, call people, or go and see people, they won't put in the effort for me, and I don't mean much to many people. So I learned that my worth is not as much as I thought it was. (Lucy)

Beyond friendships, the illness journey itself was often an isolating struggle; this was described by Freya: “the illness itself is very, the condition and what I was going through, it was a very lonely and isolating time.” With limited support available, CYP and their families often felt left to manage an overwhelming situation alone: “It was very much just me and my mum trying to figure this out on our own” (Lucy).

Over time, this prolonged isolation led to a growing sense of disconnection from school, relationships, and the world itself. CYP struggled to maintain a sense of belonging within their once-familiar worlds, leading to a sense of detachment from school and peer groups. Florence described this in terms of it feeling like “you're just in your own separate world”, or like “I was in my own little goldfish bowl”. CYP spoke of feeling like observers rather than participants in their own lives, as if the world were moving forward without them, captured by Jenny’s metaphor: “It kind of feels like you're watching through a window when your life is, like, stuck still.”

Beyond isolation, some CYP encountered social exclusion and hostility within peer interactions, to the detriment of their wellbeing. CYP’s descriptions indicated a sense of feeling like a spectacle for their peers, characterised by constant questioning, rumours, and ridicule. Meredith experienced that peers were “clearly talking about me behind my back”. Freya and Lucy extended on this:

> They were spreading, spreading rumours […] and just kind of just making those sorts of comments about how they didn't believe me and things like that. And then I think that made me, well, then I just felt even more distant from them. (Freya)

> I had most of my classmates that weren't my friends completely take the mick out of me all the time and and ridicule me for needing to like rest or take breaks in class and my friends then became sort of the public enemy with me. And they were like, we can't be seen with you. (Lucy)

4.5.2 Subtheme: Mourning the Lost Self

CYP described how ME/CFS significantly disrupted their expected life trajectory, leaving them mourning their past selves and envisioned futures. This subtheme explores their sense of identity loss, stalled adolescence, and ongoing grief, as CYP watched their peers progress whilst their lives felt frozen in time.

Disrupted academic functioning led to feelings of loss and failure, particularly when academic identity was central to CYP's sense of self. For example, Jenny described how she had always been "proud of [her]self for being quite clever", but she "had to let that go a bit, which was hard". Similarly, Florence expressed that she "ended up leaving school with about four or five GCSE's at pass. And, um, I just felt like a complete failure".

Beyond academics, school represented a cornerstone of social and emotional development for CYP. Freya reflected, "School was the only thing I'd known […] I kind of held on to [it] for some sort of normality." Disrupted participation, therefore, resulted in a fractured connection with the school community and typical experiences of adolescence:

> Obviously school is not just about like the actual learning like there's you know, friends and school trips and opportunities and like clubs and whatever […] not being able to do a lot of that kind of separates you from quite a lot of school life. (Kiara)

While peers developed as expected, CYP felt they missed key milestones of adolescence. This created a sense of loss, as Jenny described: “It's definitely not how [she] had planned [her] education journey to be,” along with a sense of stalled or stunted development:

> They all have jobs and they're all, like learning to drive, and they're all kind of looking at unis […] that is exactly what I would want for myself and kind of hurts to like, watch everybody else do that, and for me not to be able to […] there's a massive sense of like everybody else has moved on and grown up, and I feel like inside I'm still about 13 year old girl. (Jenny)

This stagnation disrupted CYP’s development of independence and social confidence. Jenny reflected on how this impacted her social development, “I really think it’s kind of like, I don’t know, stunted it”. For many, this contributed to a sense of loss: “Kind of like a mix of like mourning and grieving the the teenhood and lifehood that I could have had but won't” (Lucy).

Contrary to the expectation of adolescence as being a key time for identity formation, CYP felt as though their sense of self was eroded due to their experiences with ME/CFS. Jenny particularly highlighted the impact of this: “It kind of felt like I was having to sacrifice another piece of my identity […] it just kept taking more and more and more.” This was particularly difficult during adolescence, as Jenny acknowledged that “that’s kind of what being a teenager is all about, is like discovering who you are and things like that”. Consequently, she felt, “My identity has been like heavily shaped by ME.”

CYP navigated their changed realities and experiences of loss in alignment with the commonly recognised five stages of grief (see Figure 16; Kübler-Ross, 1969):

> *Denial*: I had a big cry afterwards and I was like, 'I don't want to do it [drop subjects]'. And you know, I resisted for a while, but then I had to drop some. (Jenny)

> *Anger*: Unfair. I think it's like I, you know, I would have liked to have seen like who I became without this and I don't... I feel like, I don't know, a bit resentful of the fact that it's like happened at such an age where it's like everything's quite like raw. (Jenny)

> *Bargaining*: If that intervention had been put in earlier and the right things had have been put in at the right time, then I probably would have salvaged a lot of my mental health. (Florence)

> *Depression*: I just remember sitting in the hallway having a little breakdown because it it made me realise how unwell I was […] I just felt very overwhelmed. (Meredith)

> *Acceptance*: It's not always gonna work, work out how you would have wanted. And I think it's it accepting that as well. (Kiara)

Figure 16

Reflexive Diary Extract 10

Grief, Identity, and the Centrality of Relationships

Attending a funeral today has influenced my reflections on the experiences shared by CYP with ME/CFS in my research. While nothing equates to grieving the loss of a loved one, I found myself considering the process of grief more broadly, how life prepares us for loss through the challenges we encounter. With this on my mind, I have been led to consider my participants' experiences of loss and disruption to identity through a lens of grief. Many CYP with ME/CFS spoke of denial, anger, bargaining, depression and acceptance, mirroring the five stages of grief (Kübler-Ross, 1969) in their reflections on what their illness had taken from them.

Experiences of loss always remind me of the importance of people, relationships, and sharing moments and memories together. I'm left today reflecting on the centrality of social interactions and experiences over things like academic grades and material items. It struck me that this resonates with what my participants shared. When the opportunities they once wished for were stripped away (academic achievements, career aspirations, physical independence), it was relationships that remained central. Applying a lens of loss and grief affords a humanistic consideration of experiences and emphasises relationships as what really matters during experiences of challenge, something that I believe schools have a central role in offering CYP with ME/CFS.

Kiara's acceptance involved acknowledging losses and adjusting to these, indicating a readiness to adapt and grow around the grief.

Many CYP did not appear to have reached a place of acceptance, however. Adjusting to chronic illness and adapting one's aspirations was a tough pill to swallow and was often associated with a lingering sense of injustice. This was expressed by Florence: "I'm still struggling now with a lot of the stuff that that went on at school because some of it was unjust. Like I didn't deserve some of the stuff that my school had put me through." Jenny similarly conveyed a sense of injustice: "There is a massive sense of 'Why did this happen to me and not anybody else? What did I do wrong?'"

4.5.3 Subtheme: Emotional Impacts

This subtheme explores the emotional impact of experiences with ME/CFS in school, including mental health difficulties, trauma-like responses to distress, and psychological coping mechanisms.

The relentless strain of navigating school with unmet needs contributed to mental health challenges, including low mood, anxiety, self-harm, and suicidal ideation. Lucy described the impacts, which led to her "turning to like self-harm and really amping up my eating disorders". Florence, similarly, shared significant impacts on her mental health:

> My mental health, it took a really bad decline in that last year at school […] I virtually got to the point where I was suicidal. I was like I just couldn't cope with what I'd been through at school because it was just it was too much. (Florence)

School was often a difficult time and became something to endure rather than experience for many CYP. Some described an emotionally detached approach to coping with school. For example, Lucy “went into autopilot and just did what I had to do to finish school […] And to just get out in, I guess, one piece”, navigating school life through a survival-based mode.

Suppressing memories of distress was another common coping mechanism. Freya attempted to “block most of these experiences out”, and Lucy “was just like, I'm gonna wipe it. I'm not gonna remember any of this. This is horrible. And I'm just going to completely disconnect from it”. As with the ‘linen cupboard metaphor’ used in trauma frameworks (Ehlers & Clark, 2000), CYP seemed to mentally ‘stuff away’ distressing experiences to avoid confrontation.

This left distressing experiences unprocessed and unresolved, thus continuing to ‘spill out’ to affect CYP years later (see Figure 17). The emotional impact was evidenced in CYP’s descriptions of the enduring psychological aftermath:

> It took me a long time to, like recover from that. Like I'd say about like 3 or 4 years and I'm still struggling now with a lot of the stuff that that went on at school because some of it was unjust. (Florence)

Figure 17

Reflexive Diary Extract 11

Blocking out the Memories: A Trauma-Informed Lens

I find myself particularly struck by descriptions of suppressing emotions and memories associated with the challenges of having ME/CFS in school. Lucy's account of blocking out these memories resonated with me, reflecting similar processes I have previously acknowledged engaging in. My emotional connection and prior interest in this aspect of experience likely influenced how I generated meaning related to this in the dataset.

The imagery of memory suppression immediately brought to mind the 'linen cupboard' metaphor often drawn upon in trauma frameworks (Ehlers & Clark, 2000), depicted below. My professional background in mental health services likely shaped my interpretation of this, although I do feel it is a valuable metaphor to acknowledge the significant distress described by CYP and the importance of support to process and make sense of this to help in the long term.

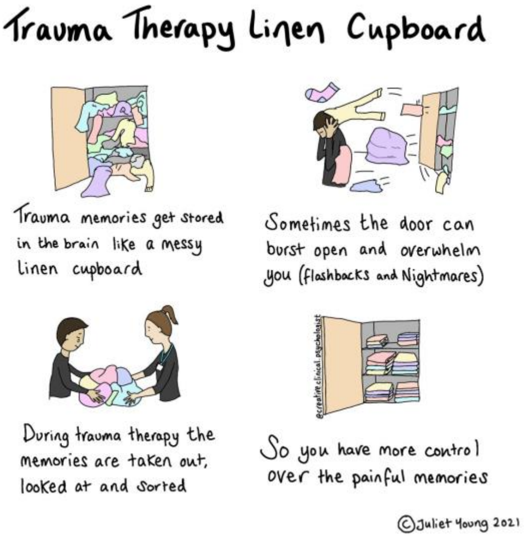


Image from 'X' by @Juliet_Young1

4.6 Theme 4: Navigating Systemic Challenges

The theme, navigating systemic challenges, explores the concept that a range of systemic barriers, related to context and time, hinder CYP's access to appropriate support within school. These barriers include misunderstanding and stigma, rigid and unresponsive systems, competing priorities between systems, and privilege and power.

4.6.1 Subtheme: Stigma and the ‘Naysayers’

This subtheme captures how stigma profoundly shapes CYP experiences of ME/CFS in school, permeating societal attitudes and filtering into school environments. A lack of awareness and understanding regarding the condition left many CYP facing disbelief, invalidation, and harmful misconceptions, creating barriers to seeking and receiving appropriate support. The stigma surrounding ME/CFS was not just an interpersonal challenge, but a systemic issue shaped by context and time.

All CYP described ME/CFS as being poorly understood across society, amongst peers, teachers, and families alike. Lucy captured this pervasiveness, commenting, “No one had ever heard of ME. No one really understood what it was. The friends, my teachers, the head, not even my parents understood. And I didn't understand either.” This was echoed by Kiara: “I think lots of people still aren't aware of it. […] they didn't know what it was or what the symptoms were or like how it affected my life.” This widespread lack of knowledge and understanding suggests that the issue extends beyond the individual level to a systemic societal disregard for developing awareness of ME/CFS.

This knowledge gap also extended to school staff, hindering CYP’s access to appropriate support. Kiara felt that the “lack of understanding” amongst teachers meant they struggled with “knowing what it is or how to go about helping you”. The lack of “resources or the experience or anything” (Jenny) amongst teachers compounded these challenges.

Stigma shaped how CYP were perceived within school, with many encountering scepticism regarding the legitimacy of their symptoms, often linked to their invisible nature. Attitudes of staff and peers often mirrored misconceptions associated with the stigmatised view of ME/CFS in society: “I think all the stigma that we see in, like, wider society […] all kind of carried over to school” (Jenny). Consequently, in school, ME/CFS was frequently disbelieved: “My SENCO didn't actually believe that ME was a real like biomedical illness or whatnot” (Florence); misunderstood as psychological: “My health was being treated as a behavioural problem” (Florence); or branded as a form of laziness: “In some people's eyes not having a real reason, being ill, and it being an invisible illness, no one's going to really see what the problem is and it looks like I'm either lying or I'm just really lazy” (Lucy).

Stigma was a significant barrier to support as it meant CYP’s needs were often dismissed. Lucy described how she felt “…very much brushed off [by school staff], 'Please stop talking about problems and making issues that, quote unquote, aren't actually there'”.

The constant need to explain, defend, or prove their condition was emotionally exhausting for CYP, leaving them feeling interrogated rather than supported. This pertained to interactions with school staff when trying to access supports like exit passes: “But no one no one adhered to that. Every time I used it, I was questioned like I was in custody and I was interrogated” (Lucy). This also pertained to peer interactions:

> I would still get questions about why I wasn't in school and constantly people were being like, 'Why did this happen? Why didn't you do that? Why did you do this? What about this?'. And I'm just like, 'Can I just exist?'. (Lucy)

For many, the pervasive stigma and disbelief led to a withdrawal from help-seeking. As a self-protective coping mechanism, some gave up on talking about how they felt or asking for help. Florence described how “some of the treatment that [she] had had in school made [her] reluctant to share [her] needs because usually they get weaponised against [her]”. Instead, CYP learnt to mask their struggles, presenting as ‘fine’ to avoid stigma, despite the significant toll on their wellbeing:

> I would push myself to come across as as OK as I can be to, I guess, get through the situation. But then also I don't want other people to feel uncomfortable with me not feeling unwell or just make it easy for others around me to just kind of act normal, so yeah. (Freya)

These experiences of stigma within school also shaped fears regarding future treatment beyond the school walls: “I think the thought process behind it was, if this is how they're gonna treat me at school, how are they going to treat me in the real world?” (Florence).

CYP overwhelmingly called for increased education on ME/CFS for both staff and peers to tackle these issues. They highlighted that “it does make a lot of difference when someone just understands” (Kiara):

> I think staff education on, like ME in particular, but also generally in terms of children with any sort of chronic health condition or whatnot, about that specific condition really helps because you're not going to bring everyone round, there's still going to be naysayers, but if people are open to the idea, they're more likely to be able to just turn around and say, 'ohh yeah, you know, I kind of understand it. I kind of get it now. I think I know how to support you better'. (Florence)

Stigma is situated within context and time. Experiences were often prefaced with their relation in time to Covid-19, indicating that a shift in understanding had already begun in the wake of the pandemic, due to increased public awareness around post-viral conditions: “Since COVID now more people are aware of it” (Kiara).

4.6.2 Subtheme: Rigid and Unresponsive Systems

This subtheme captures issues with inflexibility and unresponsiveness in school systems due to structural and attitudinal barriers. The bureaucratic nature of SEND processes and rigid approaches resulted in delays, inadequate support, and exacerbated challenges for CYP.

Some CYP described how the requirement of a formal diagnosis of ME/CFS acted as a gatekeeping mechanism to accessing timely support in school. Rather than responding to needs as reported, school procedures which required diagnosis as a prerequisite for recognition and support placed a burden of proof on CYP and families and often hindered timely access to essential adaptations. Given the pervasiveness of diagnostic delays in ME/CFS, often related to attitudes and systemic issues in healthcare, this led to prolonged periods of struggle and a lack of understanding from schools:

> It was so hard getting a diagnosis and it took up so much time and that really affected the school as well because the school were like, well, if she's not got diagnosis, then why isn't she in school. (Lucy)

> Because there was so much doubting from the medical profession, I think it was quite difficult to convince the school at first, that this was what was happening, and now, you know, they need to give me the support. (Jenny)

CYP described a conflict between SEND processes and the specific needs of ME/CFS, as the graduated approach clashed with the seemingly sudden and severe impacts of ME/CFS:

> I would have benefited from [support] being put in earlier and actually them recognising that I needed an EHCP first off the bat. None of this my plan, my plan plus stuff, because my needs in school were far outstripping what those were, and I get that they're stepping stones, but it it all happened so quickly and for for it to like gradually build up to that didn't really work in my circumstances. (Florence)

Within these rigid and unresponsive systems, some CYP viewed EHCPs as a safeguard that provides statutory protection surrounding support. Florence reflected that she thought that the approval of her EHCP “kind of mitigated [worries about help-seeking and support] a bit”. Contrastingly, without an EHCP, Jenny recalled a point in her secondary education where she thought, “An education health plan would be really nice to have about now.”

The structural separation of pastoral care and SEND within schools contributed to the fragmentation of support. Disconnection between these parts of the system promoted an either/or view of and response to needs. Systemic splitting of pastoral needs and SEN negated holistic support, which addressed the wide array of needs associated with ME/CFS, across all areas of SEND.

> I was put in pastoral care instead of SEN […] If I had have gone to the right place in the first place [SEND department], I probably would have received a better education and probably been able to leave with better grades than I did, and also in an element of it retain a bit of my social circle as well. (Florence)

Furthermore, the rigid application of standardised policies, procedures, and timetables in schools did not account for CYP’s unique needs. For example, Meredith described how she “can concentrate between 20 and 40 minutes max”, which conflicted with the demands of hour-long lessons in schools, but reflected, “obviously schools can't really be flexible about these kind of things”. Florence also described rigid school policies as a barrier to desired support:

> But the school was just not receptive to it [the idea of an AV1 robot] at all. They didn't like the thought of that, and it... I kind of get it in a way. There's the whole like, um, data protection stuff and bits and bobs. (Florence)

The hesitancy to embrace innovative or flexible solutions reflected a broader systemic issue, where schools prioritised procedural concerns over equitable access to education.

The shift to online learning during Covid-19 demonstrated that school systems could adapt their approaches to implement more flexible support, when prompted by wider contextual circumstances. For CYP who were unable to attend school full-time, the remote learning experience positively improved after the pandemic, as online learning platforms were enhanced. Whilst “before COVID […] most classes would put like the slides on Google Classroom and then I would go through the slides” (Freya), access to live-streamed lessons was facilitated post-pandemic: “The school agreed to stream lessons on Microsoft Teams for me” (Jenny).

4.6.3 Subtheme: Competing Priorities Hinder Person-Centred Care

This subtheme captures the experience of a conflict between the individual needs of CYP and the priorities of education and healthcare systems, which hinders access to person-centred care. While CYP sought holistic, person-centred care that addressed social and emotional wellbeing, schools were constrained by systemic pressures related to performance metrics, which often left their individual needs sidelined.

Constrained by accountability measures, schools were often described as prioritising attendance and academic outcomes over CYP’s health and wellbeing. System-led school priorities took precedence, often at the expense of CYP receiving appropriate holistic support. Florence felt that this resulted in a school view that “education comes first over everything else”. Similarly, Jenny experienced that “they [school] were very much, 'We provide education and nothing else'”. Prioritisation of academics resulted in less support for CYP’s social and emotional needs: “Again, the school didn't try and help. They were like, 'You don't need friends because you're doing your GCSEs. So you can revise harder.’” (Lucy).

Systemic pressures often led CYP to feel as though their value within the school was reduced to their contribution to performance metrics, rather than recognition of them as individuals with unique strengths, needs, and experiences. For Lucy, she felt “like it's got nothing to do with me. It's about the test scores that they want, and they want to have my attendance so the school attendance doesn't go down”, adding that it was “about the image of the school and nothing to do with me”. This indicated that the school system’s priorities overshadowed consideration of CYP as individuals and their personal wellbeing. Florence acknowledged the broader systemic issues likely contributing to this: “It was kind of his [headteacher’s] job to come in and […] get this school on league tables.”

Tensions between health and education system priorities led to conflicting prioritisation and advice between healthcare professionals and schools. For some CYP, this led to a dismissal of medical needs within school settings, where school staff were felt to have overstepped the boundary between their role and that of healthcare professionals in making conflicting health-related recommendations. Lucy described this as school staff “playing doctors”, as when she brought “notes from doctors and and letters and advice from medical professionals”, her head of year would push back, saying, “I just don't think that's the best advice”. Florence also described how she thought “[school leadership] didn't want to listen to [healthcare professionals] because […] it was like they were encroaching on their space and they didn't like that”. Thus, conflicting priorities and unclear role boundaries hindered joined up working and person-centred care.

Rather than their systems working in collaboration, some CYP found themselves caught in conflict between the goals of schools and healthcare providers, with detrimental impacts. For example, Florence experienced her school “trying to force [her] to come back to school full time, even against medical advice and other stuff”. This highlights the importance of respecting professional expertise in multi-agency working to support access to safe and appropriate care.

Despite statutory frameworks emphasising person-centred care within education, CYP frequently reported that this was not meaningfully implemented in practice. Where CYP’s individual needs did not fit with schools’ institutional priorities, they were often left unaddressed: “Something was offered, but I wouldn’t call it support […] It definitely didn't feel supportive to me, and maybe it was supportive to the main class because they didn't want me back in, I don't know” (Lucy).

Ultimately, systemic pressures were privileged at the expense of CYP’s individual priorities and person-centred care: “I think at the end of the day, it became a medical kind of school-focused thing for them and not a person-centred er focus which I think what it should have been” (Florence).

4.6.4 Subtheme: Identity, Power and Privilege

Experiences of navigating school systems, feeling heard, and accessing support were shaped by systemic power structures, societal beliefs, and privilege. This subtheme explores how aspects of identity related to ability, gender, and financial resources significantly influence experiences within education.

In advocating for needs and trying to participate in decision-making surrounding support in school, ableist assumptions often compounded experiences of dismissal and infantilisation for CYP, undermining their sense of autonomy. Florence described experiences of this: "...that maybe comes back a bit towards ableism, where you're often infantilised because you've got a disability.”

Gendered perceptions of chronic illness were also felt to contribute to disbelief and dismissal of symptoms:

> The perception of like chronic illness, um, it's quite often a female orientated thing. And sometimes they think that we're just malingering or like, whatnot. And I kind of feel like that maybe came into maybe a bit of play with how it was treated in school. (Florence)

Financial privilege influenced access to additional educational support. Some CYP and their families were able to afford access to private provisions to plug gaps in support within the school system: “I think I was very fortunate that my mum and my dad could afford private tuition for me” (Freya). Jenny acknowledged the disparities in access to education associated with her privilege, reflecting, “Luckily we were in a position where we could afford, like, private doctors and private education and things like that. But if we weren't, then I think we really would have struggled finding something.”

Although there was limited diversity in terms of identity characteristics within this sample, Jenny also acknowledged the likely privilege that she had been afforded associated with her race and sexuality: “But then again, I'm not... you know, I'm white and straight and you know, so maybe I... Maybe I had a good end of the stick that I didn't realise.”

4.7 Theme 5: The Power of Relationships

This concept highlights the crucial role of relationships in supporting CYP to have positive school experiences. The quality and quantity of relational experiences widely shaped CYP’s school experiences, specifically in relation to staff-student relationships, peer relationships, and relationships between the systems supporting them.

4.7.1 Subtheme: Transformative Staff-Student Relationships

School staff play a pivotal role in shaping school experiences for CYP. The presence (or absence) of supportive relationships with staff significantly impacted CYP's school experiences, wellbeing, and access to appropriate support.

Whilst CYP often described challenges in feeling seen and supported by school overall, positive relationships with individual staff members who went out of their way to understand and support them had transformative impacts on their school experiences. For Meredith, this was demonstrated by the time and resources individual staff members dedicated to supporting her to catch up after absences: "Other teachers and people higher up in school weren't so bothered about that […] whereas this teacher took time out of her lunch break." Freya conveyed just how transformational these relationships were:

> If it wasn't for her, the support teacher, then I would have... I I don't even know what my school experience would have been like. I probably would have had to drop out of school completely and probably wouldn't even have done my GCSE's, so I owe a lot of my, I owe a lot of my like support and everything to to her. (Freya)

Relational support was just as, if not more, important to CYP as academic adaptations. CYP valued staff-student relationships in which they were recognised and treated as "a whole person, not just a a brain to be taught" (Jenny). Looking beyond illness or 'student' status, to consider wider social and emotional experiences in a holistic manner was pivotal in supporting CYP to feel seen and supported within positive staff-student relationships. As Florence described, “There's so many different factors that come in, with me, to a school day. So it's just noticing that there is a bigger picture going on than the background.” Freya, similarly, highlighted the importance of this:

> Instead of making everything about, you know, education and whether they've read the book, or got these notes, it's just, you know, listening to them and understanding them and checking with them as a person and not as a student. (Freya)

Compassionate approaches, where school staff regularly checked in with CYP to listen and provide emotional validation and support, were widely appreciated by CYP when available, as Freya described: “Kindness and understanding goes a long way.” This pertained both to when CYP were present within school and unable to attend physically. In school, Meredith valued staff checking in when she felt overwhelmed: “She made sure I was ok […] I felt support then, I I felt like I had people, uhm, looking after me kind of thing.” Whilst unable to attend and learning from home, Freya valued “compassion and care before the education” from her tutor, who “would very much like listen to how my week's been and what I've been up to”. Compassionate relationships helped to mitigate feelings of isolation and reinforced a sense of worth beyond academic achievement for CYP.

Relationships built over time facilitated greater understanding and responsiveness to CYP’s needs. This highlighted the importance of prioritising building longstanding staff-student relationships within schools:

> I had like the same head of year from year 7. And I think cause I've always been very hard working and like tried my best at school and stuff, they they could see like a clear like [difference] when I started feeling very ill, they could tell […] it definitely helps them understand more. (Kiara)

However, not all students had positive experiences of relationships with school staff. Many also encountered dismissive or antagonistic attitudes, which led CYP to “question the trust” (Lucy) that they had in professionals, exacerbated feelings of isolation, and further marginalised CYP:

> It took me a long time to be able to trust people again, especially in additional learning support and like SENCO and LSAs and stuff like that, all the peripheral areas, because those were the people who I had the most contact with and some of those interactions weren't the best interactions. (Florence)

This subtheme highlights the importance of relational approaches in schools which prioritise positive, compassionate staff-student relationships for CYP.

4.7.2 Subtheme: Friendships as a Lifeline

Peer relationships play a central role in shaping how supported CYP feel in school. While some CYP found comfort and support in friendships, more support from schools to foster these social connections was needed, given the challenges of isolation and exclusion.

For those who maintained friendships, these relationships served as a protective factor to support coping in school. This included supporting emotional coping and resilience, as Kiara described: “They [friends and family] all told me that I could just do it even if I found it hard and stuff.”. Friendships also supported with advocacy in school for Meredith: “The teacher would give you a paragraph or whatever to read, and I'm just like, I can't do that. And [friend A] would be like for me, like, ‘She can't do that’.”

Informal peer support from friends also plugged gaps in practical support in school in some cases. Meredith described how her friend would “walk me to my classes sometimes when she could, so that I didn't get trampled on in the hallway or anything”, and how “not all of the classes had teaching assistants in so and I found it hard to put my hand up. So, I used to, you know, ask the person next to me about ‘What is this?’ […] and then sometimes they'll help me do it if I struggled or whatever”.

While supportive peer relationships buffered against the challenges of school life for CYP, schools often failed to recognise the importance of fostering these. This is particularly important given the widespread isolation and exclusion described by CYP in previous themes. CYP, therefore, highlighted a role for schools in prioritising and facilitating opportunities for positive peer interactions, to support them in maintaining or developing connections and experiencing the power that friendships have to offer:

> When you're not seeing people at school, friendships kind of tend to die and they [school] didn't get that. They didn't, you know, didn't think it was their job to make sure that I got some social development, but I think they maybe should. (Jenny)

School adaptations, such as remote learning and the use of inclusion rooms, inadvertently heightened experiences of social exclusion for some. For example, Jenny highlighted that during remote learning, “there was no interaction whatsoever. It would have been nice, maybe if they'd given the computer during break times and we could have a chat things like that”. Lucy also highlighted the isolating nature of inclusion rooms: “Why is sitting in Learning Support normal when all your friends are upstairs sitting in the classroom, probably giggling and doing whatnot?” This emphasises the importance of schools considering how to integrate social inclusion within educational adaptations.

Many CYP found solace in friendships with others who had shared or similar experiences. For Jenny, “it was nice to find some people who knew exactly what I was going through,” and similarly Freya found that “friends that kind of did understand and that I became closer with were also like people at school who were unwell for whatever reason and they couldn't really attend attend school”. This indicates a role for schools in facilitating these connections, where possible:

> In the ideal world, I'd have someone that going through the similar experience to me in the same school, so that even if you don't become the best of friends,

> you've got someone that understands what you're going through to talk to. (Meredith)

While positive friendships offered crucial emotional and practical support, these experiences were rare, further contributing to challenges in the school environment. This emphasises the importance of schools addressing the social dimensions of illness and disability to foster friendships and positive social experiences for CYP.

4.7.3 Subtheme: Working Together

This subtheme captures the importance of collaborative relationships between schools, healthcare professionals, external services and families. Effective communication and joined up approaches were essential in ensuring timely and appropriate support.

The process of securing support required systems to work together, including schools sharing information with families, and external services signposting to available provisions.

> It took a while to, kind of, you know, being in the inclusion room and be under her support. Because the school kept it very, very quiet and and it wasn't until I got ESMA, the educational support team, they knew about it, and then they introduced me and that's how I kind of like integrated myself under this team. (Freya)

Healthcare professionals played a key role in legitimising CYP's needs within school. Their input, through letters and meetings, was "quite instrumental in getting stuff put in like my reduced timetable" for Florence, and "really helped convince [school] to stream the online lessons and things like that" for Jenny. The power of the medical voice seemed to predominate in relationships around CYP, as Florence described: "If they [ME/CFS service] hadn't have battled that out at the start I do not know what would have happened."

Ongoing liaison across systems, through meetings and emails, was pivotal to implementing and reviewing support and ensuring CYP's fluctuating needs were appropriately met. However, access to this was variable:

> Lots of it was my mum emailing my head of year or just my teachers. And then obviously like a lot, a lot of it was me emailing my individual teachers as well […] I think it's just a big like communication thing of keeping everyone in the loop, so they're aware of what's going on. (Kiara)

> Every kind of six months we had a Teams meeting with them and my parents would be there and me and pastoral care and the other like support teachers. And we would just go over everything that wasn't working at the minute. (Jenny)

Advocacy across CYP's systems was pivotal in enacting support, particularly within schools. SENCO advocacy facilitated access to accommodations for Florence: "Once we won [the SENCO] over […] he started actually like putting stuff in place for me that I needed." Similarly, pastoral staff adopting an advocacy role to "liaise with my teachers" was supportive for Freya: "She would just kind of be in my corner if I was getting any grief or having any difficult times with my teachers," promoting more positive and supportive experiences.

When collaborative relationships across systems were established, a sense of togetherness and support within the illness journey was described. This was conveyed through repeated use of 'we' and 'us' when describing individual experiences. For example: "When we first got ill" (Jenny), and "It was all very new to us" (Freya). Joint decision-making and shared responsibility across systems fostered a sense of collective investment in CYP's education, as Meredith described: "We'd all decided that dropping a subject would help me get the best possible grades."

4.8 Chapter Summary

This chapter provided an overview of the themes and subthemes generated through RTA, exploring the school and support experiences of CYP with ME/CFS.

The secondary school experiences of CYP with ME/CFS were shaped by a pervasive sense of feeling invisible, overlooked, and disbelieved. School participation was hard work due to significant physical, academic, social, and emotional challenges. Yet, amidst these difficulties, CYP demonstrated resilience and growth through adversity.

Accessing timely and appropriate support was equally challenging. Invisibility and systemic barriers often contributed to experiences of feeling overlooked and unsupported, particularly in social and emotional domains. This created a burdensome fight for recognition, impacting help-seeking behaviours and hindering access to support. While flexible adaptations made by schools were crucial in supporting CYP, they were not consistently experienced. The power of relationships with staff, peers, and between systems was crucial in ensuring CYP felt supported and accessed necessary supports to promote inclusion.

The next chapter will further examine these findings in relation to the RQs, situating them within the existing literature and considering their implications.

5. Discussion

5.1 Chapter Overview

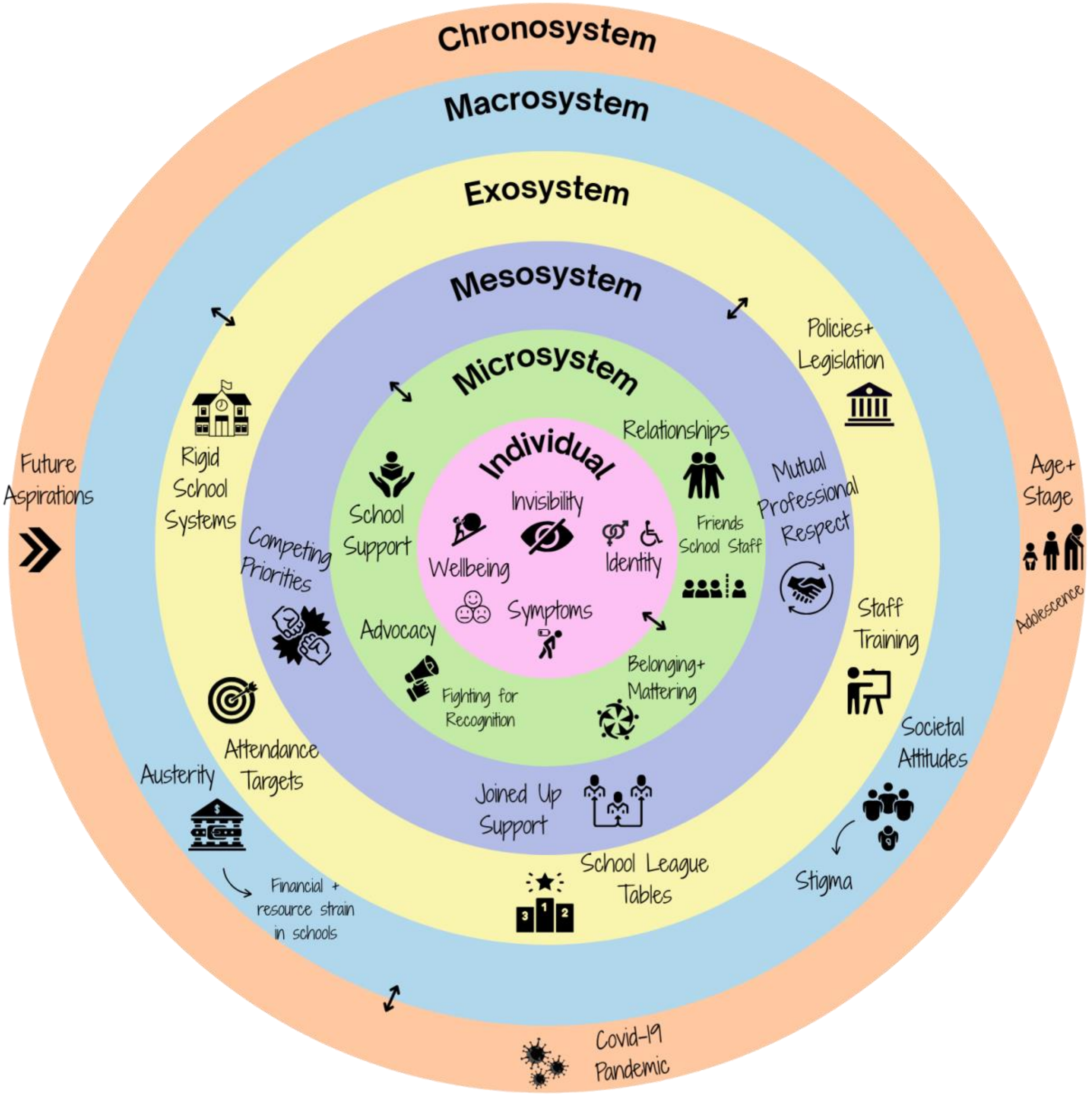
This study's exclusive focus on CYP's perspectives facilitated an in-depth exploration of the school experiences and experiences of support of CYP with ME/CFS, extending previous UK-based research. This chapter will draw upon findings to explore novel contributions of this research towards answering each of the RQs, contextualising these within existing literature and theoretical frameworks. Strengths and limitations of the study will be discussed, including the role of reflexivity in the research. Implications for the practice of education professionals, including school staff and EPs, are drawn, alongside opportunities for future research and a dissemination strategy.

Guided by the critical realist ontology and contextualist epistemology, discussion of findings recognises the reality of ME/CFS and the impacts of living with the condition, whilst acknowledging that how people interpret and respond to it is widely shaped by context. Whilst this means that experiences are not universal, themes are discussed where commonalities were drawn from the data.

To acknowledge the role of contextual factors in directly and indirectly shaping experiences, this discussion draws on Bronfenbrenner’s ecological (and later bioecological) theory (Bronfenbrenner, 1979, 1995; Bronfenbrenner & Morris, 1998, 2006) throughout (Figure 18). Other theoretical frameworks, including self-determination theory (SDT), resilience theory, narrative psychology, and systems psychodynamics, are also drawn upon to contribute to understanding findings (Figure 19).

Figure 18

An Ecological Systems Perspective on School and Support Experiences of CYP with ME/CFS



Note. Adapted from Bronfenbrenner (1979).

Figure 19

Reflexive Diary Extract 12

My Choice of Theoretical Frameworks

As I reflect on my choice of theoretical frameworks drawn upon throughout, I am aware of the influences upon my selection. As a Trainee EP at the Tavistock and Portman NHS Foundation Trust, my training has embedded a strong foundation and interest in systemic and psychodynamic theories. This frames how I view individual CYP, interactions within their environments, and the systems around them. My systemic lens led me to focus on the proximal processes between CYP and school staff or peers, as well as the broader social and policy contexts shaping experiences. Applying a psychodynamic lens also led me to consider the role of unconscious processes within organisations supporting CYP with ME/CFS.

Reflecting on these choices, I acknowledge that my own positionality, as a Tavistock trainee and someone with professional experience in schools, has inevitably shaped what I drew from the data and that another researcher may interpret findings differently.

Whilst I exercise reflexivity surrounding this, I am mindful of potential blind spots. Drawing upon my critical realist ontological stance enabled me to critically examine how underlying structures and systemic factors may shape the experiences described by CYP. Similarly, my contextualist epistemology encouraged me to situate my interpretations within their social, cultural, and historic contexts, fostering a more nuanced and context-sensitive understanding. Together, these orientations helped me to balance my own worldview with a broader systemic understanding.

5.2 Findings in Context

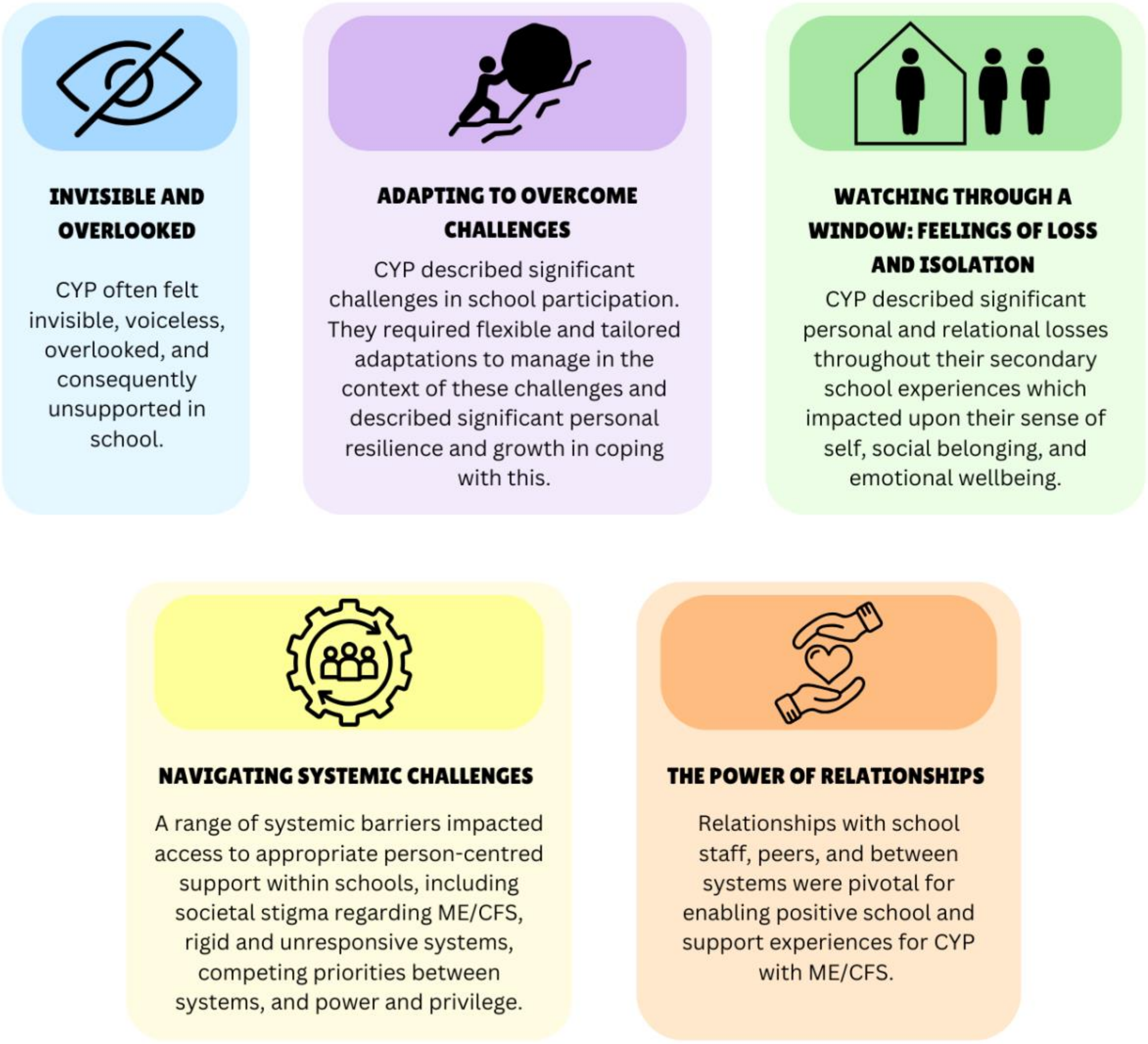
This research sought to explore the following RQs:

1. *What are the experiences of CYP with ME/CFS during secondary school?*
2. *What are CYP's experiences of support at secondary school whilst living with ME/CFS?*

Data analysis considered both RQs in unity, given the interconnected nature of school experiences and experiences of support, to generate the five themes summarised in Figure 20. This chapter will consider the contribution of these themes towards each RQ in turn to clearly address them. However, some overlaps are inevitable due to the complex interplay between school experiences and support described in Chapter 4.

Figure 20

Summary of Themes



INVISIBLE AND OVERLOOKED

CYP often felt invisible, voiceless, overlooked, and consequently unsupported in school.

ADAPTING TO OVERCOME CHALLENGES

CYP described significant challenges in school participation. They required flexible and tailored adaptations to manage in the context of these challenges and described significant personal resilience and growth in coping with this.

WATCHING THROUGH A WINDOW: FEELINGS OF LOSS AND ISOLATION

CYP described significant personal and relational losses throughout their secondary school experiences which impacted upon their sense of self, social belonging, and emotional wellbeing.

NAVIGATING SYSTEMIC CHALLENGES

A range of systemic barriers impacted access to appropriate person-centred support within schools, including societal stigma regarding ME/CFS, rigid and unresponsive systems, competing priorities between systems, and power and privilege.

THE POWER OF RELATIONSHIPS

Relationships with school staff, peers, and between systems were pivotal for enabling positive school and support experiences for CYP with ME/CFS.

5.2.1 RQ1: What are the experiences of CYP with ME/CFS during secondary school?

5.2.1.1 Statement of Principal Findings. This study highlights that there is more than meets the eye within CYP's school experiences with ME/CFS. School participation was hard work for CYP in this study, and a sense of invisibility shaped experiences. While physical challenges are well recognised, this research also highlights the less visible but significant cognitive, social and emotional difficulties in school. Despite this, resilience and growth were observed within CYP's narratives. Importantly, the study makes novel contributions by foregrounding the difficult balancing act CYP with ME/CFS face in navigating school participation, the need for support in processing emotional distress and grief associated with school experiences, and the importance of fostering mattering alongside belonging in school.

5.2.1.2 'Watching Through a Window': Feelings of Loss and Isolation

5.2.1.2.1 A Lonely Experience. An exclusive focus on CYP's lived experiences within this study contributed an in-depth understanding of the significant social isolation and exclusion experienced by CYP in school, extending existing research. Consistent with findings from Clery et al. (2022), restricted school and social participation due to ME/CFS contributed to weakened peer relationships for many; CYP often drifted apart from school friends, feeling left behind and forgotten, echoing findings from Norway (Winger et al., 2014). To some extent, this may reflect the balancing act between prioritising social or academic endeavours described by CYP in this study, which meant that CYP often had less energy to invest into social participation. This may have affected friendship stability, as research has previously highlighted the dynamic nature of friendships in adolescence and the impacts of contextual changes like these (Poulin & Chan, 2010). However, a sense of being dropped was also conveyed, with Jenny's description of "clinging on" vividly highlighting the unwanted and painful aspect of isolation, which often felt beyond CYP's control.

Highlighting the profound social and emotional costs of social isolation for CYP with ME/CFS during secondary school was a novel contribution of this study. Extending existing literature on loneliness (Brigden et al., 2021; Similä, Nøst, et al., 2021; Winger et al., 2014), this study illuminated feelings of abandonment and social disconnection, which were closely linked with diminished self-worth, wellbeing, and worries about stunted social development. Given the importance of relationships and proximal processes in child development (Bronfenbrenner & Morris, 1998), and the centrality of relatedness across theoretical frameworks such as resilience theory (Prince-Embury, 2006) and SDT (Ryan & Deci, 2000), social isolation had profound emotional implications, described in more detail under 'emotional impacts'.

The disconnection and feelings of abandonment described by CYP suggest a diminished sense of school belonging[16] and mattering[17]. Maslow's (1943) hierarchy of needs emphasises love and belonging as fundamental psychological needs. Consequently, social connections and relationships in which CYP experience a sense of belonging and mattering are essential to foster wellbeing, adjustment,

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[16] Belonging refers to "the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment" (Goodenow & Grady, 1993, p. 80).

[17] Mattering refers to the "psychological tendency to perceive the self as significant to others" (Marshall et al., 2010, p. 368). It is characterised by attention (being noticed by others), importance (feeling of being a concern of others), and dependence or reliance (feeling that others can depend on us) (Flett, 2022).

engagement and motivation for learning (Alink et al., 2023; Korpershoek et al., 2020). Consistent with research highlighting lower levels of school connectedness amongst CYP with ME/CFS in Australia (Knight et al., 2018), these findings emphasise the need to foster CYP's sense of belonging in school. The concept of mattering is novel in this area, but crucial given CYP's descriptions of feeling forgotten and abandoned.

Social exclusion was also widely described by CYP, extending previous literature on common experiences of misunderstanding, negative labelling, and disbelief from peers in school (Clery et al., 2022; Winger et al., 2014). Building on this, CYP in this study highlighted wider experiences of hostility within peer interactions in school, where they often felt like a spectacle for peers, facing constant questioning, rumours, and ridicule. Beyond further isolating CYP, this likely undermined their sense of safety in school, a foundational need within Maslow's (1943) hierarchy. Given well-established links between bullying and mental health and suicidal ideation (Li et al., 2024), this is an important aspect of experience which schools must address to support CYP's wellbeing.

***5.2.1.2.2 Mourning the Lost Self*.** Findings of this study highlight the disruption and loss CYP with ME/CFS experienced during secondary school, in relation to their expected life trajectory, identity development, and emotional wellbeing, consistent with previous research (Parslow et al., 2017; Similä, Nøst, et al., 2021). This encompassed losses recognised in the wider literature, relating to social experiences, academic self-concept, aspirations, and concerns about longer-lasting development and later opportunities (Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021).

The stage of adolescence that CYP were at during secondary school was particularly pertinent, as CYP felt that friendships were more fragile during this stage; disruptions to independence and social participation contrasted with typical adolescent trajectories (Bailey, 2006). This contributed to a sense of stagnation in identity development, which could be understood through Erikson's (1963) psychosocial development theory. This posits that identity formation is a key task of adolescence, a stage in which CYP develop a sense of self through social interactions and participation in key developmental experiences. Given the impacts of ME/CFS on CYP's participation levels, reduced opportunities to develop one's sense of self through these interactions likely contributed to the feeling of "stunted" development described by Jenny. When CYP could not attend school physically, limited opportunities to maintain social ties with peers likely perpetuated these difficulties, highlighting an important role for schools in considering how to maintain these, such as through digital technologies.

Disruptions and losses described in this study also created incongruence between CYP's current and envisioned or desired lives. Rogers' (1959) person-centred theory offers insights into the influence of this experience on psychological distress, emphasising that self-worth is dependent on congruence between self-image and the ideal self. Incongruence between CYP's aspirations, whether that be academic for Jenny or extracurricular for Kiara, and what they had the capacity to participate in due to ME/CFS, was highlighted within this study as contributing to distress. Education professionals should therefore draw on person-centred approaches to explore CYP’s ideal selves and implement support to foster congruence between this and their lived realities where possible, to support self-worth and minimise distress.

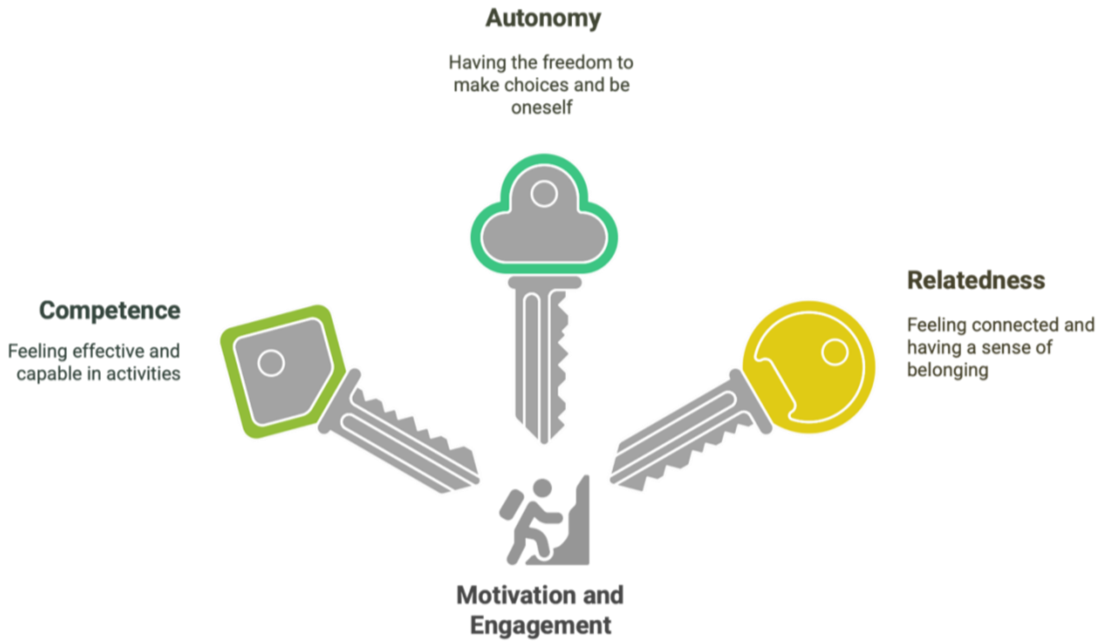
Whilst existing literature considered CYP’s losses across various domains in isolation, this research was novel in drawing an overarching theme of grief. Application of Kübler-Ross’ (1969) five-stage grief cycle supported an understanding of the process CYP go through in coming to terms with the limitations associated with having ME/CFS. This highlights the complex emotional journey experienced by CYP and offers a framework for supporting them in navigating each of these stages, towards a place of acceptance where they can ‘grow around the grief’ (Tonkin, 1996). Given the significance of missed school experiences in shaping this grief, schools have a crucial role in supporting this.

***5.2.1.2.3 Emotional Impacts*.** This research highlights significant emotional distress and mental health difficulties associated with navigating secondary school with ME/CFS. Extending beyond literature highlighting lower emotional wellbeing (Knight et al., 2018) and higher levels of mental health difficulties (Ali et al., 2019) in CYP with ME/CFS related to reduced participation (Ali et al., 2019; Parslow et al., 2020; Similä, Nøst, et al., 2021), this study links these struggles with challenging school experiences. Some CYP described attempting to suppress difficult memories, yet adverse effects often persisted into adulthood. These lasting impacts are akin to trauma processing, as metaphorically described by Ehlers and Clark (2000) as a ‘disorganised linen cupboard’ spilling open unpredictably. The application of a trauma-informed lens to understand experiences highlights the importance of providing CYP with opportunities to process distressing experiences in school to mitigate the long-term emotional and mental health impacts widely experienced in this and wider research.

SDT offers further insight into understanding the psychological challenges CYP with ME/CFS face (Ryan & Deci, 2000), depicted in Figure 21. Consistent with wider research on CHCs (Eassey et al., 2020), this study highlights challenges to key psychological needs essential for motivation and wellbeing, namely autonomy, competence, and relatedness. CYP often experienced restricted autonomy, losing control over their bodies and ability to participate in school and socially, as well as feeling voiceless and excluded from decision-making. A reduced sense of competence arose due to physical and cognitive challenges affecting participation and academic functioning, and barriers to self-advocacy, including limited knowledge about ME/CFS amongst CYP and families. Relatedness was threatened by social isolation and exclusion. These unmet psychological needs likely contribute to the emotional challenges of managing in secondary school with ME/CFS, highlighting areas to prioritise to improve experiences.

Figure 21

Depiction of Self-Determination Theory



Note. Adapted from SDT by Ryan and Deci (2000).

5.2.1.3 Invisible and Overlooked

5.2.1.3.1 Feeling Invisible and Voiceless. A pervasive sense of invisibility shaped CYP's experiences within school, building on findings from Norwegian research (Winger et al., 2014). Experiences of invisibility were multifaceted, including invisible symptoms and needs which often went unrecognised, and an invisible or overlooked presence in school, particularly during periods of absence or remote learning. This invisibility not only contributed to needs being overlooked and unsupported, as discussed under RQ two, but also to a relational sense of invisibility which widely shaped social and emotional experiences.

This research reinforced existing literature highlighting the voicelessness widely experienced by CYP with ME/CFS within school. In attempts to advocate for their needs, CYP often felt unheard and dismissed, contrasting with the importance placed upon CYP's participation in statutory frameworks (DfE & DHSC, 2015) and existing literature (Brigden et al., 2020; Clery et al., 2022). With the importance of autonomy underscored by SDT (Figure 21; Ryan & Deci, 2000), it is incumbent upon professionals to move beyond marginalisation of CYP's voices to actively listen and respect these to foster this.

While the role of mattering has begun to gain attention in healthcare research (Graney et al., 2024), its role in schools, particularly for CYP with CHCs, remains underexplored. Feeling valued, receiving attention, and feeling that people are interested in what you have to say are essential to one's sense of mattering and consequent wellbeing (Flett et al., 2018). For CYP with ME/CFS, school experiences of feeling invisible, as Lucy described, like "you don't exist", and feeling voiceless likely diminish this, exacerbating emotional challenges. This is particularly detrimental during adolescence, a critical period for self-concept development (Rosenberg & McCullough, 1981). These findings highlight the need to promote a sense of feeling seen and heard, thus mattering, for CYP with ME/CFS in school. Through this, CYP's sense of relatedness and consequent motivation, wellbeing, and resilience could be fostered (Prince-Embury, 2006; Ryan & Deci, 2000)

5.2.1.4 Adapting to Overcome Challenges

5.2.1.4.1 School Participation is Hard Work. This research highlighted significant physical, cognitive, and sensory challenges which made school participation, including attendance and academic engagement, hard work for CYP with ME/CFS.

This research uniquely highlighted CYP's perspectives on the sensory challenges that made participation in the school environment hard work. Increased noise and light sensitivity were frequently described, contributing to feelings of overwhelm within the classroom environment, which exacerbated academic challenges. This extended previous research, where primary school teachers acknowledged sensory overwhelm in loud and busy classrooms (Brigden et al., 2021), to offer insights directly from CYP about their lived experiences.

This research also uniquely highlighted the compounded difficulties faced by neurodiverse CYP with ME/CFS in managing school sensory environments. For instance, Freya's experience of being autistic and having ME/CFS amplified challenges with coping with sensory input in school. While emerging research has indicated links between chronically disabling fatigue and neurodivergent traits (Quadt et al., 2024), the intersection of experiences for CYP remains underexplored to date. This highlights the importance of developing a nuanced understanding of intersecting experiences for CYP with ME/CFS in school, an important direction for future research.

CYP in this study highlighted that physical symptoms of ME/CFS, including fatigue and PEM, significantly impacted their ability to attend school full-time, consistent with findings widely represented in the literature (Knight et al., 2018; Tollit et al., 2018). Extending on Davies' (2021) findings related to 'hidden' forms of non-attendance, this study also emphasised how physical symptoms limited CYP's engagement, even when physically present in school. For example, Freya described how she "was kind of in the lesson just to sit there and listen and observe rather than participate". This highlights the importance of flexible approaches that foster meaningful participation, whilst accommodating fluctuating levels of engagement. Whilst exosystem-based factors such as attendance policies shape a focus on physical attendance, these findings emphasise a need to consider broader engagement levels to develop a nuanced understanding of CYP's school experiences and needs.

This research extended prior findings on PEM (Parslow et al., 2017; Similä, Nøst, et al., 2021) to highlight the difficult balancing act faced by CYP in school, which was widely unrecognised by others. CYP had a limited "pocket of energy" available to them to use for daily activities, as described by Jenny. The hard work of school participation, therefore, posed a trade-off with health, exemplified by Florence, as "you had to give way to part of the curriculum, or you had to try and overwork yourself". Although not cited explicitly by CYP, the Spoon Theory[18] (Miserandino, 2003) offers a valuable metaphor to explain the trade-off of energy demands described within this study (Figure 22). Promoting its use amongst staff and CYP could address the lack of understanding highlighted in this study, help CYP to communicate their needs, and increase CYP's sense of autonomy, a key factor in SDT (Figure 21; Ryan & Deci, 2000), by enabling them to decide how they would like to prioritise their 'spoons'.

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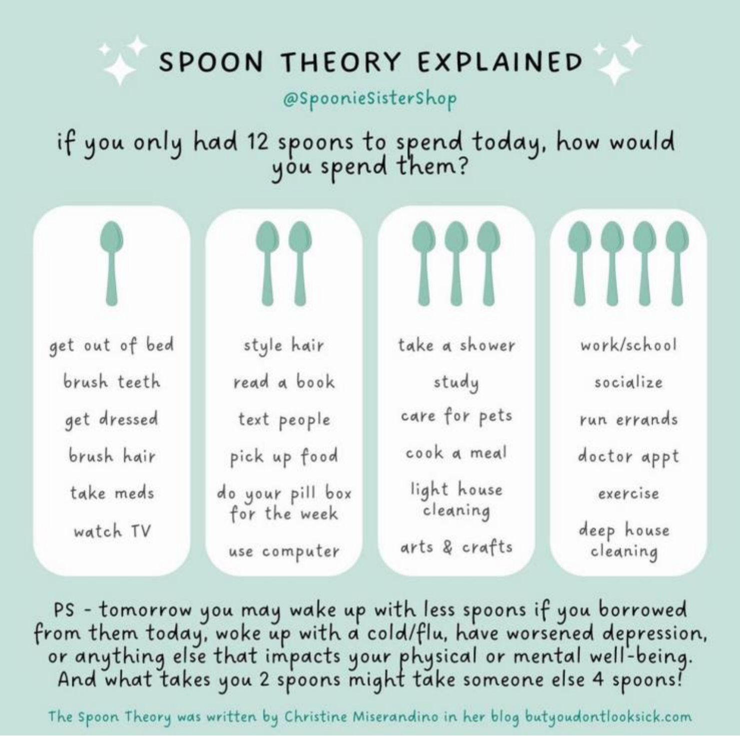
[18] The 'Spoon Theory' posits that people with energy limiting chronic illnesses have a limited number of 'spoons' (energy). Each activity demands a certain number of spoons (amount of energy), so these 'spoons' must be rationed carefully to manage an individual's energy levels and health (Miserandino, 2003).

Figure 22

Visual Representation of the Spoon Theory



SPOON THEORY EXPLAINED

@SpoonieSisterShop

if you only had 12 spoons to spend today, how would you spend them?

get out of bed
brush teeth
get dressed
brush hair
take meds
watch TV

style hair
read a book
text people
pick up food
do your pill box for the week
use computer

take a shower
study
care for pets
cook a meal
light house cleaning
arts & crafts

work/school
socialize
run errands
doctor appt
exercise
deep house cleaning

PS - tomorrow you may wake up with less spoons if you borrowed from them today, woke up with a cold/flu, have worsened depression, or anything else that impacts your physical or mental well-being. And what takes you 2 spoons might take someone else 4 spoons!

The Spoon Theory was written by Christine Miserandino in her blog butyoudontlooksick.com

Note. Image from ‘Facebook’ by @SpoonieSisterShop.

The physical, cognitive, and sensory ‘hard work’ of school participation contributed to difficulties with academic functioning for CYP in this study, consistent with prior research (Clery et al., 2022; Parslow et al., 2020; Parslow et al., 2017). In particular, CYP described how cognition and learning challenges, reflective of ME/CFS symptoms (Rowe et al., 2017), made keeping up academically difficult, consistent with prior research. This was closely linked with the ‘mourning the lost self’ theme, as feelings of loss and failure related to this were expressed, including concerns about the long-term impacts of this on exam results and future prospects. This was consistent with previous research with this age group (Davies, 2021; Lewis, 2022; Parslow et al., 2020). Pressures on CYP to achieve high grades in their GCSEs likely contribute to these concerns, linked with factors at the exosystem level within the UK context (Torrance, 2004). Thus, in addition to exam arrangements, CYP with ME/CFS may benefit from guidance and planning surrounding appropriate post-16 pathways.

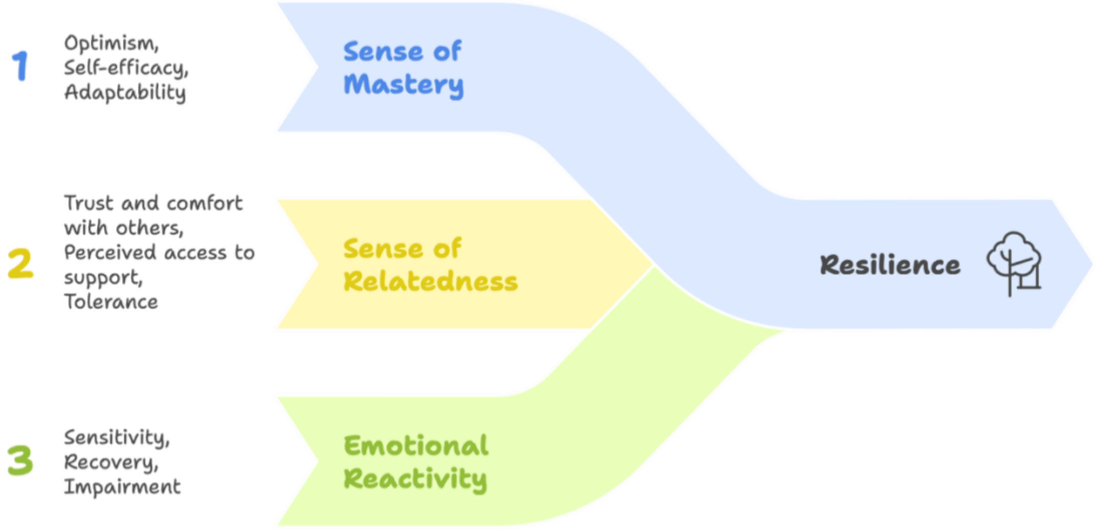
5.2.1.4.2 'It Makes You More Resilient'. This study extended the understanding of how CYP with ME/CFS show resilience in the face of adversity within school. In addition to holding a positive and hopeful outlook, consistent with findings from Parslow et al. (2016), CYP in this study showed resilience through their adaptability in response to school challenges. This included working around difficulties, prioritising subjects, and adapting to learn from home.

Redefining their sense of success was also crucial, enabling CYP to celebrate their accomplishments relative to the challenges, like Jenny's celebration of achieving five GCSEs when she'd doubted being able to complete any at one point. However, consistent with previous thesis research (Davies, 2021; Lewis, 2022), this was not easy for all CYP, as Kiara, for example, struggled with lowering her aspirations. This indicates a need for support in processing these challenges in order to foster a resilient outlook.

Theories of resilience can be applied to further understand factors supporting CYP's resilience in this study. Prince-Embury (2006) conceptualises resilience as comprising a sense of mastery, relatedness, and emotional reactivity (Figure 23). Expanding on this, Ungar et al. (2013) emphasise the role of proximal processes and sociocultural context in cultivating resilience, highlighting the critical role of CYP's systems, such as school, in fostering this. This study highlights that CYP's adaptability and optimism likely support resilience through contributing to a sense of mastery. Similarly, where CYP redefined success to support coping, this may indicate strengths in recovery, a key factor in emotional reactivity.

Figure 23

Components of Resilience Theory



Note. Adapted from resilience theory by Prince-Embury (2006).

Within the current study, resilience and coping were often tied to a sense of relatedness, feeling supported by friends, family, or school staff. However, experiences of feeling disconnected from school, unheard and delegitimised in interactions likely threatened this. Feelings of helplessness and the loss of autonomy described previously may have further hindered coping by diminishing CYP's sense of mastery. This underscores the need for schools to address systemic factors at the various levels of a child's ecosystem, rather than focusing solely on the individual, to promote resilience by fostering a sense of mastery, relatedness, and emotional resilience.

This study also highlights how CYP with ME/CFS construct resilience and personal growth narratives in response to adversarial school experiences. Narrative psychology posits that the stories individuals construct about their lives shape identity, experiences, and coping. In this study, stories related to growth appeared supportive of navigating challenges in school. Frank (1997) described three common illness narratives, namely restitution[19], chaos[20] and quest[21], which provide a valuable lens for interpreting these findings, as previously done so for adults with ME/CFS (Whitehead, 2006). CYP in this study often framed their experiences in quest narratives, widely describing becoming 'more resilient' following the adversity they faced in school, showing perseverance and developing transferable skills like self-advocacy, adaptability, and a resilient mindset. However, chaos narratives were also observed within accounts, reflecting a sense of helplessness from their loss of autonomy. This demonstrates the importance of attending to the emotional and narrative dimensions of experiences and fostering autonomy to promote resilience and coping.

Reflection upon post-adversarial growth within this research is likely to have been facilitated by the retrospective approach. Tedeschi and Calhoun's (2004) posttraumatic growth model emphasises that reflection is key to recognising personal growth as it facilitates cognitive appraisal and meaning-making. In the current study, the passing of time between school experiences and research

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[19] A restitution narrative focuses upon the hope of recovery. Illness is viewed as a temporary disruption which can be overcome.

[20] A chaos narrative describes illness experiences characterised by feelings of overwhelm, helplessness, loss, and limited agency. This narrative is associated with significant disruption to a person's life.

[21] A quest narrative frames illness as a journey towards personal transformation, as the person finds meaning or growth through the experience.

participation likely supported this growth. This indicates that CYP with ME/CFS in school are likely to benefit from opportunities for reflection to help them reframe experiences and build resilience, particularly following links between their distressing school experiences and the processing of these in ways akin to trauma.

Whilst positive narratives were often described within this research, a paradox was noted, where CYP frequently expressed gratitude for experiences despite widely feeling unsupported. In the absence of perceived access to support, seeking positives and practising gratitude may have buffered against reduced levels of relatedness to foster resilience and coping. In relation to Prince-Embury's (2006) resiliency model, when a low sense of relatedness in school was experienced, this paradox may be reflective of CYP's attempts to mitigate this by clinging to optimism to promote a sense of mastery. Whilst gratitude can be a helpful exercise for supporting coping for some (Ghosh & Deb, 2017), it is not appropriate for all and is not a substitute for genuine support. This emphasises the importance of applying an ecosystemic lens when conceptualising resilience for CYP with ME/CFS (Ungar et al., 2013) to ensure they feel supported in school. Such a lens requires attention to microsystemic interactions between CYP, school staff, caregivers, and peers, mesosystemic processes such as interactions between home, school, and healthcare, and distal interactions at the exosystemic level, which shape the availability of relationships and support (Ungar, 2015).

5.2.2 RQ2: What are CYP's experiences of support at secondary school whilst living with ME/CFS?

5.2.2.1 Statement of Principal Findings. This study importantly extends beyond the challenges faced by CYP with ME/CFS in school, to explore their experiences of support and hopes for how schools can adapt to better support them. Findings highlight that CYP with ME/CFS widely feel overlooked and unsupported in secondary school, with their support experiences shaped by a pervasive sense of invisibility and systemic factors, including stigma and rigid school structures. However, there was more going on for CYP than met the eye; while support tended to prioritise physical needs, Social, Emotional and Mental Health (SEMH) needs were often overshadowed and necessary flexible, individualised support was not consistently available. Whilst the fight for recognition and support was widely recognised in previous literature, this research uniquely highlighted the burden of self-advocacy for CYP and consequent impacts on help-seeking beliefs, masking, and access to support. To overcome barriers to support, education for school staff and peers alike, an emphasis on supporting SEMH needs, and prioritisation of compassionate and collaborative relationships were widely called upon by CYP in this study.

5.2.2.2 Adapting to Overcome Challenges

5.2.2.2.1 Beyond One-Size-Fits-All. CYP in this study emphasised the importance of flexible approaches, tailoring support to respond to individual needs, to support inclusion in school. This aligns with a social model of disability[22] (Oliver,

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[22] The social model of disability (Oliver, 1983) frames disability as arising from the a mismatch between a person's needs and their environment, facilitating a more holistic view of experiences.

1983), which posits that schools should adapt to meet CYP’s needs, and is consistent with prior research (Similä, Rø, et al., 2021). However, this conflicted with a ‘one-size-fits-all’ approach often felt to be applied, where schools often “stick to the prescribed stuff”, as described by Florence, rather than creatively tailoring adaptations.

Building on Davies’ (2021) research, this study illuminated a hierarchy of support. Physical accommodations, such as reduced timetables, rest breaks, access to alternative spaces, remote learning, and exam arrangements, were most commonly accessed, reflecting those frequently cited in existing literature (Brigden et al., 2021; Clery et al., 2022). These adaptations may be more readily implemented because they respond to more visible and understood needs and align with existing school practices. In contrast, support for less visible needs, such as cognitive, social, and emotional needs, was less consistent. These findings reinforce the need for more holistic and flexible approaches in schools, moving beyond reactive, surface-level accommodations to explore the breadth of individuals’ needs and tailor support accordingly.

Findings from this study indicated an important gap between espoused flexibility in support and actual experiences of inclusion. While staff often report embracing inclusive values and flexibility in the support they offer CYP with ME/CFS (Brigden et al., 2021; Similä, Rø, et al., 2021), this study highlighted a different felt reality for some CYP. Flexibility mainly involved adaptations in which CYP were expected to step back from demands, rather than schools adapting the learning environment or teaching approaches to facilitate true and equitable inclusion. This was further compounded by accommodations such as remote learning or access to alternative spaces, which, though intended to support and experienced positively by some, left others feeling isolated, reducing their sense of inclusion within the school community. This extends findings from Davies (2021), who illuminated unintended consequences of school support, such as unintentionally promoting exclusion, and extends Webster's (2022) concept of the 'Inclusion Illusion'[23] to apply to support for CYP with ME/CFS.

Inclusion challenges when supporting CYP with CHCs in school have long been recognised (Mukherjee et al., 2000). From an ecological perspective (Bronfenbrenner, 1979), access to flexible, individually tailored holistic support may be hindered by systemic factors, such as austerity, at the macrosystem level, affecting financial and resource strain in education despite increasing numbers of CYP with SEND, and exosystem pressures linked with school accountability measures (National Audit Office, 2024; Ofsted, 2025). This is corroborated by recent research highlighting that the inclusion of CYP with CHCs in schools may be hindered by factors like insufficient staff time, high pupil numbers, and focus on performance metrics (Herlitz et al., 2025). This indicates a need to address these broader systemic challenges to ensure that schools are equipped to foster genuine inclusion through flexible and tailored adaptations for CYP with ME/CFS.

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[23] The 'Inclusion Illusion' describes findings by Webster (2022) that CYP with SEND often face separation and segregation in their daily educational experiences as the organisation of schools and classroom practices lead to a form of structural exclusion, despite inclusion being espoused.

5.2.2.3 Invisible and Overlooked

5.2.2.3.1 Overlooked and Unsupported. CYP in this study often felt overlooked and unsupported in school. Reflective of much of the existing literature (Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021), difficulties with securing basic adaptations, gaps in support, inconsistent implementation of agreed support, and inappropriate expectations placed upon CYP undermined equity and inclusion and exacerbated challenges described under RQ one.

SEMH needs were particularly overlooked for CYP with ME/CFS, reflecting the hierarchy of support described previously. While this builds on previous research with CYP (Davies, 2021), it contrasts with primary school teachers' reports of social and emotional support implementation (Brigden et al., 2021). This discrepancy reinforces the mismatch between teacher and CYP's perspectives highlighted in Chapter 2 and gaps in secondary school SEMH support structures (Spernes, 2022). This reflects a broader pattern within the literature, which tends to prioritise symptoms, functional impairments, and observable impacts of ME/CFS over psychosocial dimensions. This bias may stem from the dominance of the medical model[24] in this predominantly healthcare-led research landscape.

Framing through a medical model of disability likely contributes to the dominant restitution narrative (Frank, 1997) identified amongst school staff by CYP within this study; staff were perceived to prioritise support related to symptom mitigation, recovery and returns to normal school functioning, such as regular

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[24] The medical model conceptualises disability as resulting from the symptoms or impairments in a body system or function, and thus focuses on these as the barrier to participation (Olkin, 1999).

attendance, at the expense of SEMH support. Applying a social model of disability offers a valuable reframe, shifting the focus of support from individual impairment towards creating environments which acknowledge and respond to the full spectrum of CYP's needs, including SEMH. Figure 24 illuminates reflections on the exploration of models of disability within this research.

This study builds on the limited evidence base exploring CYP's perspectives (Clery et al., 2022; Davies, 2021) to highlight that feeling overlooked and unsupported also often leads to an emotional sense of neglect and heightened anxiety in school. Perceived low levels of support challenged CYP's sense of relatedness, a critical factor for resilience, motivation and wellbeing (Prince-Embury, 2006; Ryan & Deci, 2000), and their fundamental need for a sense of safety and security within school (Maslow, 1943). Thus, beyond the practical implications of feeling unsupported, this experience has broader emotional implications for coping in school.

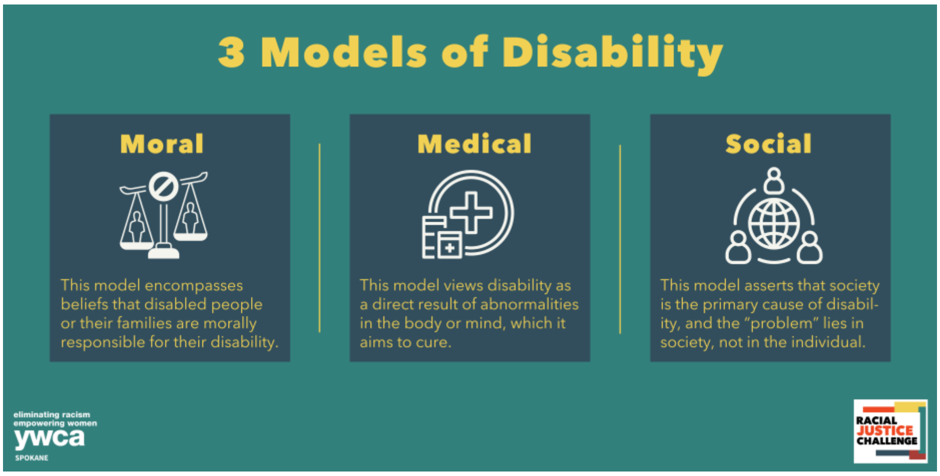
Figure 24

Reflexive Diary Extract 13

What about Religion and Spirituality?

Reflecting on the medical and social models of disability and how my participants' experiences can be understood through these, I am aware of the absence of attention towards the moral/religious model of disability (Henderson & Bryan, 2011) during interviews and the process of generating themes.

Outlined in the figure below, this model often explains disability as a punishment for sins or a test of faith. In the context of ME/CFS, this view could shape experiences by further reinforcing negative stereotypes and blame for some, although could also offer strength to individuals, fostering resilience and spiritual growth.



3 Models of Disability

Moral

This model encompasses beliefs that disabled people or their families are morally responsible for their disability.

Medical

This model views disability as a direct result of abnormalities in the body or mind, which it aims to cure.

Social

This model asserts that society is the primary cause of disability, and the "problem" lies in society, not in the individual.

eliminating racism
empowering women
ywca
SPOKANE

RACIAL
JUSTICE
CHALLENGE

Image from 'YWCA Spokane'

Although I asked a question about the role of identity factors, such as religion, in experiences, no participants mentioned religious or spiritual influences within interviews. As someone who is not religious and does not consider this an important aspect of my own identity, I wonder about my own role in shaping this omission. While it is possible that participants didn't feel it to be an important factor, there remains the possibility that it was. It is possible that CYP may have found it difficult to share this invisible aspect of their identity, for example due to fear of judgement, or due to cultural norms related to feeling comfortable/appropriate discussing religion or spirituality in a formal research context.

Given the importance emphasised by CYP of considering their holistic experiences, greater exploration of the role of religious or spiritual views and their role within ME/CFS school experiences may be an important area for practitioners and future researchers to consider.

***5.2.2.3.2 Fighting for Recognition*.** This study uniquely emphasises the toll on CYP of trying to secure recognition and support in school, which is widely experienced as a fight or battle to avoid being overlooked. Barriers to self-advocacy, including ME/CFS symptoms, staff awareness and disbelief, school resistance, and power dynamics, created an adversarial process. While previous research highlights the burden of advocacy on parents (Clery et al., 2022; Herlitz et al., 2025), this study highlights how the energy spent fighting for support further drained CYP's capacity for meaningful school participation. Furthermore, despite their fight, CYP widely felt their voices were unheard, disbelieved, and excluded within interactions surrounding their care, consistent with findings from Herlitz et al. (2025).

When support was available, CYP were often positioned as responsible for navigating this and self-regulating their needs, such as independently deciding when to take rest breaks. While this supports autonomy, a key factor in fostering motivation and wellbeing (Figure 21; Ryan & Deci, 2000), it places additional cognitive and emotional demands on CYP to self-monitor their needs and enact self-advocacy efforts. These findings extend Davies' (2021) observation of the burden of self-advocacy, highlighting potential impacts on fatigue. This reduced CYP's energy available for meaningful participation within the school environment, as Jenny described how the limited energy that she had was spent trying to access learning rather than engaging with it. Furthermore, difficulties with self-advocacy may reduce help-seeking efforts and consequent access to support, as Kiara described how the last thing she wanted to do when feeling unwell was think about her support needs.

Application of narrative theory highlights the role of language, social and cultural contexts and discourses in shaping meaning (Bruner, 1990). War metaphors of a “fight” and “battle” used by CYP within this study about seeking support reflect broader adversarial narratives in the SEND system (Cullen & Lindsay, 2019) and CHCs (Herlitz et al., 2025). While such metaphors help articulate complex experiences, support externalisation[25], and validation of experiences (White & Epston, 1990), they may also reinforce struggles, exacerbating worries related to needs being met in school, fostering distrust and internalised stigma, and a sense of defeat (Nelson, 2001; Schon, 1979). This may perpetuate issues and further deter self-advocacy efforts for CYP with ME/CFS.

Reframing dominant narratives could foster more empowering perspectives, through deconstructing and re-authoring limiting dominant cultural narratives (White & Epston, 1990) or developing a generative metaphor to encourage new ways of thinking about a problem (Schon, 1979). For example, Jenny’s metaphor of education as a ”journey” aligns with a quest narrative of illness (Frank, 1997) and has been found to be a helpful alternative to war metaphors in other medical conditions (Reisfield & Wilson, 2004). However, it is important to avoid invalidating the metaphors that CYP choose to use as these reflect genuine meaning-making and experiences of adversity. Recognising the power of language in shaping help-seeking experiences offers an opportunity for schools and professionals to support CYP in articulating and reflecting on their own metaphors, as a narrative approach

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[25] In narrative therapy, externalisation refers to the act of expressing a client’s problem as a separate entity from the person or their identity. It promotes the view that “Neither the person nor the relationship between persons is the problem. Rather, the problem becomes the problem, and then the person’s relationship with the problem becomes the problem.” (White & Epston, 2005, p. 74). This view renders problems as less fixed and restricting.

that balances validation with the possibility of shifting discourses and fostering more constructive narratives around support.

5.2.2.4 Navigating Systemic Challenges

5.2.2.4.1 Stigma and the 'Naysayers'. A widespread lack of knowledge and understanding about ME/CFS shaped support experiences for CYP in this study, consistent with previous literature discussed in Chapter 2. In Kiara's words, this exacerbated challenges by hindering access to appropriate support, as teachers lacked understanding relating to "knowing what it is or how to go about helping you". This knowledge gap is linked with previous research highlighting limited information and training about the condition for school staff at an exosystem level (Brigden et al., 2021) and, more widely, ME/CFS has historically been under-researched at a macrosystem level (DHSC, 2024). Consequently, CYP in this study advocated for increased staff education on ME/CFS, aligning with previous research (Clery et al., 2022). Work at the exosystem level to improve knowledge, understanding, and visibility of the condition, such as through training, is crucial to improve support experiences and CYP's sense of relatedness in school, a key factor contributing to resilience (Prince-Embury, 2006).

Extending these findings, this study highlighted how stigma in school shaped CYP's beliefs about support and help-seeking, both in education and beyond. Misunderstanding and disbelief prevalent amongst staff and peers resembled societal stigma, permeating school environments. Mirroring reports of low confidence in receiving appropriate help for ME/CFS in healthcare (Pheby et al., 2020), CYP in this study often encountered scepticism, delegitimisation, and denial of access to adequate school support, shaping expectations within this context too. Due to this, many participants felt their best chance at inclusion was to remain silent about their struggles, using masking[26] as a self-protective coping mechanism, rather than seeking support for their needs.

Masking in school of ME/CFS needs, or CHCs more broadly, is an area previously underexplored. Due to experiences of stigma, CYP often downplayed or concealed their symptoms, like Freya describing how she would “push [her]self to come across as as OK” as she could. This was a key barrier to support needs being recognised by school staff and CYP seeking and accessing support. Although a novel contribution of this research, this finding is supported by previous research highlighting that masking occurs across neurotypes, driven by stigma and perceptions of difference (Miller et al., 2021), and research linking a fear of rejection or pity with decisions to conceal invisible conditions (Kaushansky et al., 2017). Since masking can have detrimental impacts on adults' identity, stress and exhaustion levels (Miller et al., 2021), it likely exacerbates physical, cognitive, and emotional challenges for CYP with ME/CFS. This underscores the need for further research and efforts to reduce stigma to improve help-seeking experiences and access to support.

Experiences of delegitimisation also raised concerns about the future for CYP. Participants questioned how they could expect accommodations and inclusion in wider society if even schools, which are meant to be supportive environments,

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[26] Masking is a term widely used in relation to neurodiverse conditions, describing the suppression of aspects of the self and identity, either consciously or unconsciously, in social situations to either go unnoticed or fit in (Miller et al., 2021). It is also sometimes termed ‘camouflaging’, ‘compensation’ or ‘adaptive morphing’.

overlooked and disregarded their needs. While chronic illness stigma, internalised shame[27], and reluctance to seek help are documented in adults with Multiple Sclerosis (Barta & Kiropoulos, 2023), this study highlights a similar issue in ME/CFS school experiences. Given the importance of help-seeking in accessing necessary adaptations and support, this has concerning implications for CYP's long-term health, wellbeing and ability to advocate for their needs, particularly in a society which is not yet proactively responsive to needs associated with invisible conditions like ME/CFS due to issues and attitudes at the macrosystem level (Bronfenbrenner, 1979). Addressing stigma and establishing responsive school support systems is, therefore, crucial for improving immediate support experiences and equipping CYP to navigate future challenges beyond the school environment.

Despite recurrent experiences of stigma, findings from the current study highlight the role of time in shaping attitudes surrounding ME/CFS, emphasising the chronosystem's role in shaping experiences of support (Bronfenbrenner, 1979). Covid-19 was used as a reference point in time by many CYP in this study, with Kiara highlighting the increased awareness surrounding ME/CFS that arose following this. This reflects how sociopolitical events can disrupt dominant narratives and shift public discourse, potentially creating space for greater epistemic recognition of conditions like ME/CFS (Fricker, 2007). This indicates a hopeful outlook that, with systemic work to push the ME/CFS agenda, increased understanding can be developed and support experiences further improved for CYP in schools over time.

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[27] Internalised shame is defined as "the emotional experience of negative self-evaluation and is linked to self-related cognition and affect" (Barta & Kiropoulos, 2023, p. 134).

5.2.2.4.2 Rigid and Unresponsive Systems. Rigid school policies and procedures at the exosystem level constrained flexibility and timely responses to CYP's diverse and fluctuating needs in this study. For example, CYP widely described that schools required confirmation of diagnosis before implementing school support, consistent with prior research (Brigden et al., 2020; Brigden et al., 2021; Lewis, 2022), despite this being contrary to statutory guidance (DfE & DHSC, 2015). Furthermore, Florence described how the graduated approach to SEND support led to her needs "far outstripping" the support available, due to prolonged evidence-gathering and the stepped nature of support. Delays in support associated with system rigidity conflict with the sudden increase in symptom intensity experienced by Florence and common in ME/CFS (Rowe et al., 2017). Addressing systemic issues to improve flexible and timely access to support is particularly crucial to prevent PEM and worsening symptoms resulting from unmet needs for CYP with ME/CFS. As schools demonstrated a readiness to enact change in response to more widespread Covid-19 contextual pressures, such as through improvements to remote learning through online learning platforms, this indicates a role of the chronosystem, alongside wider exosystemic and macrosystemic influences, in driving change.

A novel finding of this study was how the structural separation of pastoral care and SEND within secondary schools exacerbated challenges in accessing holistic support. CYP often experienced either SEND or pastoral provision, but not both, as Florence described being "put in pastoral care instead of SEN". Exosystemic factors, such as policy-driven division of provision, may drive this.

This novel finding can be understood through a systems psychodynamic perspective, where splitting in organisations serves as an unconscious defense mechanism to manage anxiety (Menzies Lyth, 1988). Previous research highlights that teachers are often fearful of the risks of supporting CYP with CHCs (Hinton & Kirk, 2015). Thus, struggling to balance medical, psychological, social, and academic needs, schools may compartmentalise or ‘split’ responsibilities, creating an illusion of control at the expense of addressing needs holistically. This siloed approach may have contributed to the fragmented experiences of support described in this study. Menzies Lyth (1988) argued that organisational containment is crucial for managing anxieties within caregiving institutions. Thus, designing school systems to provide effective containment for staff could improve joined up and holistic care.

While the main structure for support was described by many CYP as an EHCP, IHPs were notably absent from CYP’s accounts. Given that IHPs are recommended within statutory guidance (DfE, 2015) and designed to be developed collaboratively with CYP, families, and professionals, their omission could indicate limited awareness, usage, or perceived effectiveness, which requires further exploration. The emphasis on EHCPs, which are more rigid, formal, and legalised, may be indicative of a tendency towards preference for clearer structures and frameworks which provide clear boundaries, creating a sense of containment in the face of managing the uncertainty and complexity of supporting CYP with ME/CFS (Green & Molenkamp, 2005). This, again, highlights the importance of containment within systems to facilitate the adoption of flexible, responsive approaches to support.

5.2.2.4.3 Competing Priorities Hinder Person-Centred Care. Consistent with findings from Clery et al. (2022) and Herlitz et al. (2025), CYP in this study described how school systemic pressures, such as attendance targets and league tables, prioritised such academic metrics over person-centred care responsive to broader needs, like social and emotional wellbeing. As Jenny described, her school's stance felt very much like “we provide education and nothing else”. While policies acknowledge the importance of SEMH support (DfE, 2021; Oftsed, 2023), performance and accountability measures for secondary schools (DfE, 2025) place greater emphasis on achievement and attendance. Furthermore, priorities within healthcare systems related to health and recovery meant that tensions within the mesosystem between health and education overshadowed individual needs. To rebalance the prioritisation of needs within support planning, accountability measures should emphasise SEMH outcomes and CYP's participation in decision-making to drive exosystem-level change.

A novel finding of this study was the high level of awareness held by CYP regarding these competing systemic pressures surrounding support, whilst previous research primarily explored this through parental and professional perspectives (Clery et al., 2022; Herlitz et al., 2025). This awareness could have negatively impacted CYP's sense of mattering in school, as school support priorities taking precedent may convey a sense that CYP's individual preferences, strengths, and needs are less important or valued within the school community. This highlights how school approaches to support can impact CYP's wellbeing, emphasising the importance of centring CYP in decision-making. While this awareness may have developed through cognitive reappraisal due to the retrospective nature of this study, exploration of CYP’s sense of mattering in school is crucial, given this.

***5.2.2.4.4 Identity, Power and Privilege*.** This study uniquely highlights how identity, power, and privilege mediate access to support; this area is largely unexplored in existing research. Support experiences were mediated by identity characteristics such as ability, gender and financial position. Whilst largely unexplored in CYP and school contexts, this aligns with research with adults with CHCs highlighting marginalisation related to gender, class, and racial identity (Au et al., 2022; Evenson, 2021). Thus, factors at the person level interact with systemic barriers within the macrosystem to influence CYP’s experiences (Bronfenbrenner, 1979). For example, the current study reflected existing research, highlighting the gendered nature of health-related stigma (Devoto, 2022). Intersectionality theory suggests that overlapping disadvantages can create a new type of oppression (Crenshaw, 1989). For example, female gender and invisible disability contributed to perceptions of “malingering” for Florence. Given links between social power and epistemic trustworthiness (Fricker, 2007), individuals positioned at the intersection of multiple social disadvantages may face diminished trust and support from professionals due to the impacts of minority stress (Meyer, 2003). These findings build on concerns raised in Chapter 1, by evidencing how epistemic injustice and systemic inequities are experienced by CYP in school, shaping their access to recognition, validation, and support. This is an important issue requiring further exploration due to the limited diversity within the current study sample.

Financial privilege also shaped access to support, enabling private tuition and additional resources. Some participants hypothesised that their privilege positively influenced school support and experiences, however, homogeneity within the sample negated further exploration of this. Considered alongside evidence related to disparities in access to diagnosis for people living in areas of multiple deprivation (Ponting & Samms, 2024), this indicates a need for policy to further explore and address these socioeconomic disparities.

5.2.2.5 The Power of Relationships

***5.2.2.5.1 Transformative Staff-Student Relationships*.** Findings from the current study highlight the transformative role of supportive staff-student relationships. In line with theory underscoring the importance of proximal processes between CYP and their immediate environments (Bronfenbrenner & Morris, 1998) and previous literature (Parslow et al., 2016; Similä, Nøst, et al., 2021), the quality of relationships and interactions with school staff had pervasive impacts upon support experiences. Relational and compassionate approaches were a protective factor for CYP in navigating secondary school, as with previous thesis research (Davies, 2021; Lewis, 2022), and humanistic theories emphasising the importance of a sense of safety, security, love, and belonging (Maslow, 1943). These approaches were characterised by support in which CYP felt understood, valued, and emotionally supported through validation, check-ins, and practical advocacy. This supported wellbeing and mitigated some of the challenges of navigating secondary school with ME/CFS.

Not only do teachers have a pivotal direct role in providing emotional support and fostering belonging within school, but Runions et al. (2020) also highlight their positive indirect influence on peer interactions for CYP with CHCs. This resonates with findings from the current study, which highlight the important role of schools in fostering positive social experiences for CYP with ME/CFS to promote belonging, mattering, and relationships.

However, consistent with previous research (Clery et al., 2022; Parslow et al., 2017; Similä, Nøst, et al., 2021), not all CYP experienced positive staff-student relationships. In some cases, antagonistic or dismissive responses contributed to experiences of marginalisation and a breakdown of trust in professionals.

The application of a systemic lens contributes to an understanding of the adversarial staff-student interactions described within this study. Smyth and Blitshteyn (2025) posited that adversarial interactions in healthcare are perpetuated by the emotional state of both practitioners and patients, shaping language and interaction patterns. They suggested that practitioners' anxiety surrounding complex and poorly understood conditions like ME/CFS may influence their language use and communication styles, at a time when patients, influenced by past adversarial experiences and dominant narratives, are particularly sensitive to such interactions. The circularity[28] within such interactions can be observed, where challenges in navigating support are perpetuated within a feedback loop (Bateson, 1972). This could be applied to understand CYP's experiences of delegitimisation within the

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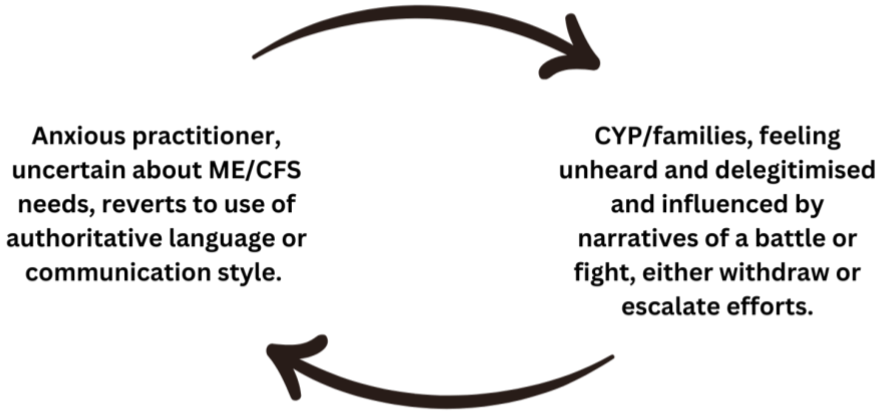
[28] Circularity is a central concept in systemic theory, describing how connections between different parts of a system interact to influence one another through feedback (Bateson, 1972).

current study, given parallels with limited understanding amongst school staff (see Figure 25). Given the important role of proximal processes in shaping experiences (Bronfenbrenner & Morris, 2006), this emphasises the importance of communication styles adopted by education professionals and ensuring that support is in place to manage anxieties within the system to foster compassionate and relational approaches.

Figure 25

Feedback Loop within Interactions Between CYP with ME/CFS and School Staff



Note. This feedback loop was inspired by the writing of Smyth and Blitshteyn (2025).

Given the importance of relationships and relatedness to resilience, wellbeing, motivation and engagement (Maslow, 1943; Prince-Embury, 2006; Ryan & Deci, 2000), an absence of relatedness or negative experiences can have significant impacts on coping, wellbeing, and later outcomes for CYP. Within the current context of high levels of pressure being placed upon school staff, finding the time and capacity to nurture positive relationships is likely to be particularly challenging. Rather than placing the burden on individual school staff, systemic approaches are required to prioritise relational approaches in schools through structural supports such as training, policies, and dedicated time for relationship development.

***5.2.2.5.2 Friendships as a Lifeline*.** Whilst negative social impacts predominated within CYP’s experiences and the existing literature, the current study also highlights that friendships were a lifeline for CYP who were able to maintain these. Retained friendships were a protective factor, maintaining some sense of belonging and mattering for CYP. Extending Davies’ (2021) findings on mutual understanding within positive friendship experiences, this study also highlights the role of friends in supporting emotional coping, advocacy, and even plugging gaps in practical support, as described by Meredith. This extends understanding of the importance of schools fostering relatedness amongst peer groups to support coping in school.

The critical role of friendships highlights the importance of schools fostering peer connection through their support. Jenny and Lucy’s experiences suggest that well-intentioned adaptations can inadvertently reinforce social exclusion by distancing CYP from their peers, through remote learning or the use of inclusion rooms. This highlights the importance of considering the potential inadvertent exclusionary impacts of support strategies. Furthermore, this study expanded on research showing the value of connecting peers with shared or similar experiences through online spaces (Brigden et al., 2018), suggesting a role of schools in facilitating such connections amongst students, where possible. Following the importance of belonging, mattering, and relatedness referred to throughout this chapter (Maslow, 1943; Prince-Embury, 2006; Ryan & Deci, 2000), such approaches are crucial to support CYP's resilience, motivation, and wellbeing.

5.2.2.5.3 Working Together. The findings of the current study also highlight that positive experiences of support were dependent on systems working together collaboratively. Joined up, multi-agency working between health, education, and families is underscored within statutory guidance (DfE & DHSC, 2015) and existing research on ME/CFS in schools (Brigden et al., 2020; Clery et al., 2022). Whilst joined up care may be challenging due to reasons discussed prior, such as time and resource pressures and competing priorities between systems, ongoing liaison and review across systems was pivotal in facilitating positive support experiences for CYP in this study and thus requires consistent prioritisation and sustained commitment from all stakeholders.

5.3 Strengths and Limitations of the Research

5.3.1 Strengths

A strength of this study was the flexible and inclusive research approach, which facilitated the participation of CYP with ME/CFS and addressed the critical gap of their often-unheard voices. Various reasonable adjustments were implemented to ethically and meaningfully amplify the voices of CYP with lived experience. The use of the GEM as an interview tool enabled a more participant-led approach, enabling CYP to steer the interview towards topics they deemed most important. Furthermore, the visual format provided a practical cognitive scaffold, supporting CYP to structure their thoughts and manage brain fog symptoms.

The retrospective nature of the study facilitated reflections upon experience, such as post-adversarial growth, which may not have surfaced for CYP when in the midst of secondary school. While concerns about potential re-interpretations of experiences associated with temporality were initially considered a limitation, a reflexive approach embraced the influence of methodology choices on the data, facilitating the contribution of novel findings in the context of children with CHCs.

The critical realist ontological and contextualist epistemological positioning of this research facilitated exploration of how CYP experienced school and support with ME/CFS, whilst also interrogating the broader systemic factors shaping these within context.

The use of RTA was a further strength of this study as it facilitated reflexivity on the role of the researcher (Wilkinson, 1988). As an insider-outsider and practitioner researcher, reflexivity enabled consideration of the influence of the researcher's personal and professional experiences, beliefs, and values. Given the contextualist epistemology of this research, this was particularly useful in recognising and transparently highlighting how the researcher influenced the process and findings of the research (Madill et al., 2000). Throughout the process of the research, the use of a reflexive journal supported reflexivity (Figure 26; Braun & Clarke, 2022).

Figure 26

Reflexive Diary Extract 14

Becoming The Object Of My Own Gaze

Regularly writing in this reflexive journal and becoming the object of my own gaze, as described nicely by Lazard and McAvoy (2020), has been transformative in extending my internal dialogue, deepening my self-awareness, and enabling me to scrutinise my assumptions and decisions throughout this research journey.

Engaging with both sameness and difference between myself and my participants has been central to my reflexivity. While I shared my female gender and childhood experience of ME/CFS with participants, differences such as my recovery status and professional role critically highlights the limits of my perspective. Acknowledging my partial and positioned perspective (Lazard & McAvoy, 2020) has helped me to critically reflect on what I can see and understand. Aspects of sameness in my lived experience may have predisposed me to focus on findings that aligned with my own assumptions (such as the experience of loss, social exclusion, and feeling let down). However, aspects of difference also shaped my interpretations (for example, my practitioner role as a Trainee EP working with schools meant that I was particularly attuned to the systemic pressures they face, which may hinder their ability to fully meet CYP's needs despite their best intentions).

Supervision further contributed to reflexivity. The reflective and containing space provided within supervision supported the researcher in recognising their feelings and responses, applying additional scrutiny, and illuminating blind spots.

5.3.2 Limitations

This was a small-scale study, involving semi-structured interviews with six CYP. As with qualitative approaches, findings are not intended to be universally generalisable, but instead to provide rich, contextualised findings (Braun & Clarke, 2022). Given the many factors shaping experiences across different relationships, systems, contexts, and time, findings are unlikely to be transferable to all experiences. Nevertheless, this study demonstrated transparency regarding the research context, participants, and processes to support the reader in evaluating the applicability of findings to their context and drawing relevant implications.

Participants were recruited online, primarily through local ME/CFS support groups. The self-selected recruitment strategy may have overrepresented CYP with particularly salient experiences, while limited advertisement reach contributed to regional homogeneity. Additionally, limited diversity regarding ethnicity and socioeconomic background restricted exploration of the role of aspects of identity, power and privilege in shaping experiences. The underrepresentation of participants from Global Majority groups reflects existing literature and may be a consequence of disparities in access to diagnosis (Nacul et al., 2011; Ponting & Samms, 2024) or minority stress (Meyer, 2003). Despite efforts to recruit broadly, limited responses underscore the need for inclusive strategies to build trust and reach Global Majority groups.

Conducting research with CYP with ME/CFS presents unique challenges, including fluctuations in symptoms such as brain fog and fatigue. Flexible adaptations, such as breaks, split sessions, and trusted adult support, enabled participation. However, their influence on the data must be acknowledged (Figure 27). For Kiara, breaking the interview up over multiple sessions fostered rapport through prolonged participant-researcher engagement; however, this may have disrupted flow and depth within interviews. For Meredith, the presence of a trusted adult supported with brain fog but may have shaped what was and was not discussed. These complexities highlight the importance of flexibility and transparency in qualitative research with this population.

Figure 27

Reflexive Diary Extract 15

Reasonable Adjustments and Power in Data Collection

(This extract was written immediately after my interview with Meredith)

Interviewing Meredith today highlighted both the necessity and complexity of making reasonable adjustments for CYP with ME/CFS in research. To support her understanding due to brain fog I simplified language, repeated questions, and summarised more than in previous interviews I'd had so far. While these adjustments improved accessibility, they also raised epistemological questions about how much my summarising shaped the data we co-constructed. Did this subtly steer her responses, despite my aims to reflect her meaning?

I've also been thinking about the influence of having a trusted adult present in Meredith's interview. Initially, I was wary of her mum being involved in the interview; I entered the interview with the assumption that this may contribute to the power imbalance within the interview and reduce emphasis on CYP voice. However, observing her mum's role as a memory prompt and provider of emotional support at times shifted my perspective; her presence seemed to have enabled rather than constrained Meredith's voice. This made me reflect on the importance of parents in advocacy efforts. It also helped me to reconsider the hidden influence of parental perspectives across interviews; even where parents weren't present, their narratives likely shaped how CYP thought about and described their experiences.

That said, the possible influence of this adjustment on what was or wasn't shared by Meredith must be acknowledged. For example, Lucy articulated differences between her views and her mother's during her interview, which may have been less likely to be shared if she was present as a trusted adult.

Meredith also commented that she needed a trusted adult present because she often forgets things that happens in meetings about her care. This forced me to confront the power imbalance inherent in this research. While I retain control over the data and analysis, she and other participants may not even remember everything that they shared. This raises an ethical tension: how can I ensure participants feel ownership over their contributions when cognitive impairment limits recall? Participants kept their GEM grids after interviews, and I intend to share a summary of the research with participants to attempt to mitigate this issue to some degree.

5.4 Implications for Practice

This research explored secondary school experiences and experiences of support for CYP with ME/CFS. Exploration of CYP's challenges, positive experiences, and hopes for others in the future contributed towards practical implications, relevant to a range of education professionals, to better support CYP with ME/CFS in secondary schools.

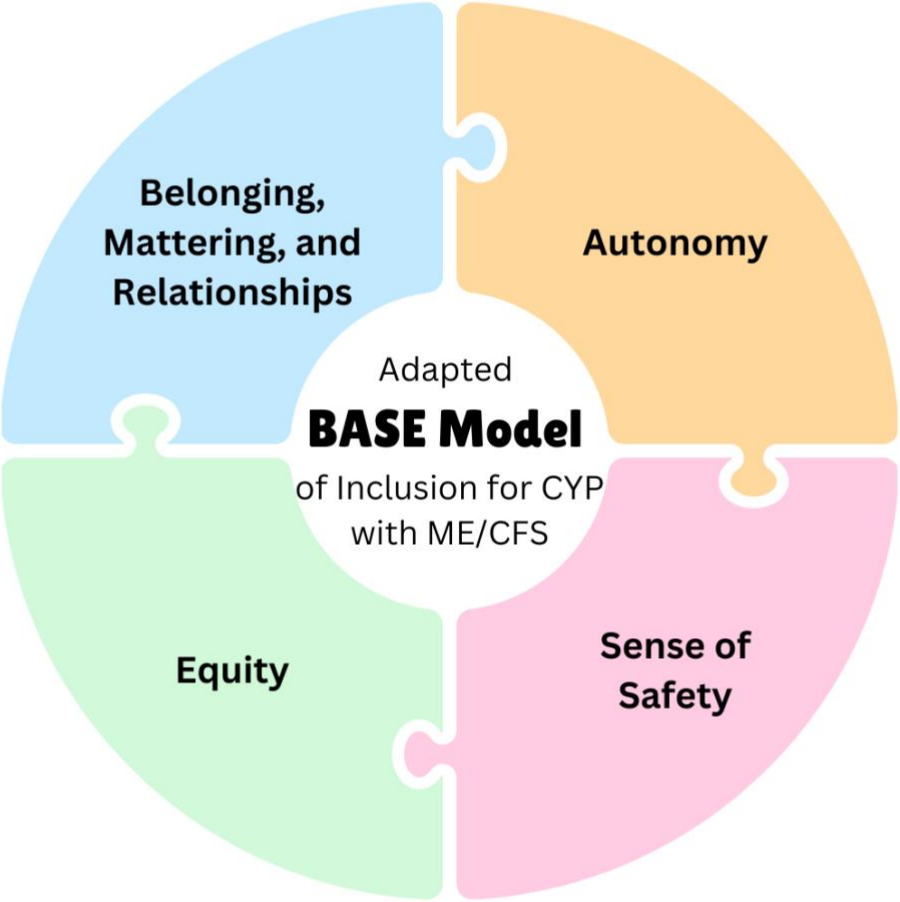
Ultimately, findings highlight the importance of adapting practice to promote true inclusion for CYP with ME/CFS. Inclusive and equitable education and learning environments which meet the needs of diverse learners are advocated by UNESCO (2015), as well as the Equality Act 2010 and SEND Code of Practice (DfE & DHSC, 2015). Whilst, at present, there is no universally accepted definition of inclusion (Williams-Brown & Hodkinson, 2021), it has previously been suggested to encompass physical placement and presence, academic participation, social participation and belonging, and achievement (Ainscow, 2006). Thus, findings from this study and the wider policy and research landscape indicate a need for inclusive practice which adopts a holistic focus to support CYP with ME/CFS in schools.

Insights from this study highlight the need for inclusive practice. Therefore, a theory-driven approach was applied by adapting Carr's (2025) 'BASE' model of inclusion to inform implications for practice. The BASE model is grounded in evidence related to what works in promoting inclusive practice, emphasising the importance of belonging and relationships, autonomy, sense of safety, and equity. Based on this study's findings, the researcher adapted this model to propose an inclusion framework for CYP with CHCs like ME/CFS in secondary schools (Figure

28). The concept of mattering was added as an extension to this model, reflecting the importance of this concept within the current study.

Figure 28

BASE Model of Inclusion for CYP with ME/CFS



Note. This model was adapted from the BASE Model of Inclusion by Carr (2025).

In line with the theoretical framing of the current research, this adapted model considers implications at various levels of a child's ecosystem (Bronfenbrenner, 1979, 1995; Bronfenbrenner & Morris, 1998, 2006). As such, this model is intended to guide practical considerations for education professionals at various levels, spanning proximal processes through school interactions to the roles of external professionals and broader systemic implications related to policies and context. Based on the adapted model, the researcher has created a BASE toolkit for inclusion of CYP with ME/CFS to detail practical implications and recommendations for school staff, EPs, and school systems (Appendix S).

5.4.1 Belonging, Mattering & Relationships

The importance of compassionate relationships and CYP feeling a sense of belonging and mattering within school is threaded throughout themes related to invisibility, isolation, and relationships, and further grounded in humanistic and resilience theory (Maslow, 1943; Prince-Embury, 2006). Through both whole school systems and micro practices, approaches should be implemented to ensure that CYP feel seen, heard, and socially included (Greany et al., 2024). At a whole school level, relational and compassionate policies, key adult systems, and prioritisation of social opportunities within timetabling are crucial. Within interactions, micro practices from school staff, such as regular check-ins and showing interest beyond academics, demonstrate compassion and care to foster belonging and mattering. These practices should continue during periods of absence to maintain connection. When planning and prioritising CYP’s time and energy demands within school, time devoted to such relationship-based activities should be considered and prioritised, given the balancing act highlighted by CYP in this study. Fostering belonging and mattering in schools should address the hierarchy of support highlighted within this study by ensuring that support for SEMH needs of CYP with ME/CFS are considered alongside other areas of need.

This research's themes of relationships and systemic issues emphasise a need for education professionals to develop joined up and collaborative working relationships, both across systems, between education and healthcare, and within them, such as within schools and between SEND and pastoral teams. To further promote holistic and joined up support for CYP with ME/CFS, the researcher has developed a Holistic Support Plan (HSP) template (Appendix T) which should be agreed and reviewed collaboratively between CYP, families, and all professionals. Since IHPs and Individual Education Plans (IEPs) used within schools serve different but overlapping functions[29], the HSP comprehensively incorporates medical, educational, and SEMH needs to streamline support and ensure that SEMH needs like belonging and mattering are not overlooked.

5.4.2 Autonomy

Findings related to invisibility and voicelessness highlight the need for education professionals to promote autonomy for CYP with ME/CFS in schools, particularly in support-related interactions. This is further emphasised by the role of autonomy in SDT (Ryan & Deci, 2000) and UK statutory guidance, which highlights that CYP should be actively involved in decisions about their support (DfE & DHSC, 2015). Schools and EPs should therefore work to remove barriers to self-advocacy and amplify CYP's voices in decision-making.

To empower CYP, explicit instruction in self-advocacy skills and knowledge of the self, rights, communication, and leadership skills should be provided (Test et al.,

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[29] IHPs typically focus exclusively on medical needs and management, whilst IEPs typically focus on educational support and adaptations required.

2005). Introducing Miserandino’s (2003) ‘Spoon Theory’ could help CYP make informed decisions about energy management and foster effective communication and understanding with staff, promoting a shared understanding and greater autonomy.

Environmental modifications to support self-advocacy efforts are also critical. Education professionals should draw on strategies responsive to individual strengths and needs to capture pupil views, such as through visual tools like the GEM used within this study. Decision aids, such as option grids like those developed in mental health services (Wolpert et al., 2019), could provide a starting point for support options for CYP and families to discuss with schools about how to tailor them to match CYP’s individual preferences and needs.

All professionals must centre CYP’s voices within decision-making to foster autonomy, ensuring collaborative development of HSPs. At a whole school level, frameworks should be established which position CYP as active participants in negotiating support arrangements and incorporate feedback mechanisms responsive to the voice of the child.

5.4.3 Sense of Safety

Education professionals must foster a sense of relational, emotional, and physical safety and security for CYP with ME/CFS within school (Greany et al., 2024), particularly given challenges highlighted within this research, despite it being a fundamental human need (Maslow, 1943).

Addressing stigma around ME/CFS is essential to promoting a sense of relational and emotional safety. Given the lack of knowledge about ME/CFS in schools and wider society, highlighted in the current and wider literature (Brigden et al., 2021; Clery et al., 2022), knowledge gaps about ME/CFS should be addressed amongst both staff and peers. This is evidenced as a successful approach in combating stigma (Salinger, 2020). External professionals, such as healthcare professionals or EPs, could support with training and planning of peer education sessions to build staff competence and confidence. Keicher et al. (2024) have developed an education programme about ME/CFS for CYP, families, and schools; when their evaluation is published, this protocol may support in the development of training and peer education in schools if evidence indicates its efficacy. However, as anti-stigma interventions are most effective when delivered by teachers (Salinger, 2020), schools should deliver student education sessions themselves to maximise efficacy in reducing adversarial interactions and promoting social inclusion, acceptance, and reducing stigma.

Considering the physical, cognitive and sensory challenges experienced by CYP in the school environment, designing accessible and inclusive school environments is crucial to promoting safety. HSPs should consider individual needs, such as sensory sensitivities, accordingly. Greany et al. (2024) suggest that inclusive school environments include quiet spaces with trusted adults available for CYP to access as needed throughout the school day. Such safe spaces, where CYP can go to relax and express their struggles without judgement, are particularly vital given findings related to masking.

Trust-building is crucial to promoting safety and security and to developing relationships in which CYP feel a reduced need to mask their symptoms. Reliable key adults who understand the condition and can advocate for CYP's needs in school should be available to build CYP's trust in help-seeking and professional support. Schools should also develop frameworks which support the consistent implementation of support plans to reduce the unpredictability and anxiety related to needs being met. Summarising needs within a clear, accessible HSP that is available to all staff, including supply teachers, could support with this.

CYP in this study highlighted significant threats to emotional safety due to distressing and delegitimising experiences within school. This necessitates careful consideration of language and communication styles with CYP and families to ensure that compassion is communicated (Smyth & Blitshteyn, 2025). Furthermore, emotional support within school to process loss and distressing experiences, feel supported, and build resilience is crucial to support coping. Regular check-ins with a key trusted adult, as well as targeted SEMH support, such as from an Emotional Literacy Support Assistant (ELSA) or other mental health professional within school, could support with this. In light of the findings around the use of metaphors, professionals could draw on narrative approaches to validate the ways CYP make meaning of their experiences, whilst supporting them to explore whether alternative narratives or metaphors, such as the 'quest' narrative (Frank, 1997), might offer more empowering ways of understanding and navigating their challenges. For example, the 'Beads of Life' (Portnoy et al., 2016) could offer a useful narrative intervention to support with this. Staff working with CYP should also receive emotional support, such as supervision from an EP, to contain their anxieties and support effective and compassionate communication and interactions with CYP (Smyth & Blitshteyn, 2025).

5.4.4 Equity

Equity[30] implies a concern with fairness (Ainscow, 2020) and is a crucial underpinning of the UK Equality Act 2010 and UNESCO (2015) guidance. To move beyond the inclusion illusion highlighted within this study, schools must move beyond accommodations that merely reduce demands and instead proactively adapt learning environments to enable equitable participation in education, in line with the social model of disability (Oliver, 1983).

Rather than requiring CYP to fit into rigid structures, schools should proactively adapt to enable participation, attending to CYP's holistic needs spanning physical, sensory, cognitive, social and emotional dimensions. Schools should offer inclusive classroom strategies, such as proactively checking in with CYP, adjusting environments, implementing assistive technology where appropriate to reduce the cognitive load, and offering flexible learning pathways, such as blended approaches that combine in-school and evidence-informed remote learning provisions (DfE, 2024; Education Endowment Foundation, 2020). A holistic approach to inclusion should extend beyond academics to ensure that CYP have equal opportunities to participate in wider activities, including social interaction with peers, moving beyond the current hierarchy of support.

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[30] Equity involves ensuring that all CYP have access to the resources and opportunities that they need to thrive, recognising that different CYP have different needs related to this. Unlike equality which treats everyone the same, equity acknowledges that some CYP may require additional support to overcome barriers in order to achieve similar outcomes (Jurado de Los Santos et al., 2020).

Whilst a graduated approach to SEND support should be followed (DfE & DHSC, 2015), this should not be at the cost of implementing timely, responsive support. Upon presentation of needs, a collaborative meeting between schools, CYP, families, and healthcare professionals should be facilitated to develop a shared understanding of strengths and needs and to co-develop a HSP to promote equity and inclusion, with regular reviews scheduled. EPs could provide support with this, given their expertise in consultation and intervention (BPS, 2022).

Findings indicate that power and privilege shape access to support, warranting further attention to inequities affecting CYP with ME/CFS at the intersection of multiple social disadvantages. Schools and policymakers must actively address systemic barriers that disadvantage CYP from minoritised groups to work towards a truly inclusive education system for all CYP with ME/CFS.

5.4.5 Application of the Model

This adapted BASE model offers a holistic approach to promote the inclusion of CYP with ME/CFS in secondary schools. It is applicable at both whole-school and individual levels and could potentially be relevant for other CHCs.

EPs have a role in promoting inclusive education (BPS, 2022). They are well-positioned to drive organisational change by supporting the implementation of this model, given their expertise in systems and relationships, such as through training, policy development, or staff supervision (Farrell et al., 2006). Solution-focused approaches could be drawn upon as an effective strategy to promote positive change in school systems (Morgan, 2016) through the application of the BASE model. EPs can also apply this framework in consultation, intervention design, and staff training to support at both individual and whole system levels.

Implementation of this model requires wider systemic change. At the exosystem level, this should include incorporating CHC awareness into initial teacher training, streamlining school support structures to support holistic support planning rather than fragmented efforts, prioritising social and emotional wellbeing within school accountability measures, and fostering closer collaboration between healthcare and education professionals.

Alongside application of the model, the researcher reflected on personal implications of the research journey, described in Figure 29.

Figure 29

Reflexive Diary Extract 16

Reflecting on Personal Implications

As I come to the end of my research journey, I reflect beyond the professional implications to think about how it has shaped me as a practitioner-researcher. Amplifying unheard voices has always motivated me. Approaching this research, I was nervous about gaining access to participants with ME/CFS, as this is a particularly quietened group in society. After some initial (expected) recruitment challenges, I was struck by the eagerness of CYP to contribute to this research and the depth of their reflections. This reinforced the importance of not making assumptions about whether CYP may be able to contribute their views and approaching pupil views with optimism and flexibility.

Findings around the ‘inclusion illusion’ have made me critically reflect on *intention versus impact*. Even well-intended support can have unintended consequences, such as social exclusion or reinforcing difference. In my practice as a Trainee EP, this has prompted me to consider the broader impact of interventions, adopting a more holistic lens. This reaffirms the importance of centring CYP voices to ensure support is genuinely inclusive.

Engaging with CYP’s lived experiences has extended my understanding of the challenges that education professionals must consider, but I was also struck by the resilience they demonstrated in coping with significant adversity. Whilst EPs often focus on difficulties, this emphasises the power of celebrating and harnessing strengths, driving me to incorporate aspects of positive psychology within my practice to support this.

5.5 Directions for Future Research

Future research could evaluate the effectiveness of implementing the adapted BASE model to promote positive experiences and support for CYP with ME/CFS in secondary schools. As the toolkit was based on what the researcher deemed salient within the current research, further research could refine and validate this resource with input from a range of stakeholders, including a diverse sample of CYP, educators, families, and healthcare professionals. Given the prevalence of narratives surrounding challenges, an appreciative inquiry research approach, focusing on practices that facilitate positive school experiences, could support this toolkit's development.

The HSP developed as part of this research, which combines key aspects of IHPs and IEPs to streamline support, should be further explored within research to consider key information that should be included and how best to communicate this in an accessible way to promote consistency in support implementation.

There is a paucity of research exploring how intersecting identities, such as ethnicity, socioeconomic status, and neurodivergence, shape school and support experiences for CYP with ME/CFS. Future research with a diverse sample of CYP could adopt an intersectional lens to explore how power, privilege, and systemic inequities affect access to support. To support the recruitment of a diverse sample, future researchers should prioritise prolonged engagement with communities underrepresented in existing ME/CFS research. This may include collaboration with trusted community stakeholders, such as charities, organisations, and local support groups, to help build trust and improve accessibility of the research. Participatory approaches with CYP, such as co-producing research questions and methods, and incorporating member checking, could also facilitate engagement and promote inclusivity. Researchers should ensure that research processes and materials are equitable, culturally sensitive, and responsive to the diverse needs of participants.

While masking is frequently explored in neurodiversity research, it has received limited attention in the context of CHCs like ME/CFS. Given the significant toll of masking highlighted within this study, further research should explore the experience of masking symptoms in school and strategies to foster inclusive environments in which CYP feel safe to express their needs.

Finally, findings indicate significant systemic barriers to inclusion for CYP with ME/CFS within education. Scant research has explored the perspectives of school leaders and policymakers in the context of support for CYP with CHCs like ME/CFS, despite their role in shaping support systems. Future research could investigate barriers and facilitators from the perspective of professionals working at the systems level to explore how to promote systemic change and inclusion.

5.6 Dissemination Strategy

The dissemination plan for this research will seek to ensure widespread impact and application of findings. Participants will receive a summary of the findings, accompanied by the adapted BASE model for inclusion of CYP with ME/CFS in secondary schools. This will also be shared with organisations that expressed an interest in the research during recruitment.

Findings will also be distributed amongst the EP community through multiple channels. Findings will be shared with the wider doctorate course during an end-of-year event to promote awareness, discussion, and potentially inspire future research. The researcher intends to present findings and the model of inclusion to the EP Service, where they are employed, to promote awareness and implementation within practice. To support wider dissemination and contribute to the limited evidence base, the researcher hopes to publish the research in a professional journal. Given the current paucity of research exploring lived experiences of school support for CYP with CHCs such as ME/CFS, the researcher advocates for a special journal edition on CHCs, to which this study could make a valuable contribution.

To effect change in applied settings more broadly, the researcher is seeking to contribute to professional guidance currently being written about working with CYP with ME/CFS in education. There is also consideration of writing an informal blog post to promote awareness of key findings and the model of inclusion for school staff.

5.7 Conclusions

In conclusion, this research amplifies the voices of CYP with lived experience of ME/CFS, illuminating their experiences, strengths, and challenges in navigating secondary school and support within it. While schools were often responsive to physical and cognitive needs associated with ME/CFS, the research highlights that there is more to CYP's experiences than meets the eye. The invisibility of the condition, delegitimisation, and overlooked SEMH needs contributed to feelings of loss, isolation and a lack of support, exacerbating challenges for CYP. These findings underscore the need for a holistic, person-centred approach.

CYP's experiences were situated within a context where systemic barriers, including stigma, rigid policies, and competing priorities between systems, impacted their access to timely, appropriate person-centred support. Despite these challenges, a sense of relatedness, fostered through quality staff-student and peer relationships, often supported coping and resilience.

Given the significant impact of school experiences on academic, social, and emotional experiences of CYP with ME/CFS, education professionals must take proactive steps to improve inclusion and support. Findings emphasise the importance of fostering belonging, mattering, and relationships, autonomy, a sense of safety, and equity in schools. This informed the development of the adapted BASE model for inclusion and accompanying toolkit, providing a practical framework to support education professionals, including school staff and EPs, to promote positive and supportive secondary school experiences for CYP with ME/CFS.

While limitations, such as the small and relatively homogenous sample, are likely to affect the transferability of findings, this study lays a foundation for future research, which should explore diverse and intersectional experiences and evaluate the contribution of the adapted BASE model in promoting inclusion for CYP with ME/CFS.

Ultimately, this research addresses a critical gap, ensuring the voices of CYP with ME/CFS are heard and their needs recognised and offering novel contributions by doing so. Deepening understanding of their school and support experiences, this research serves as a stepping stone for meaningful change, promoting inclusive and supportive school environments for a historically overlooked group.

“There is always another story, there is more than meets the eye” (Auden, 1945, p. 199)

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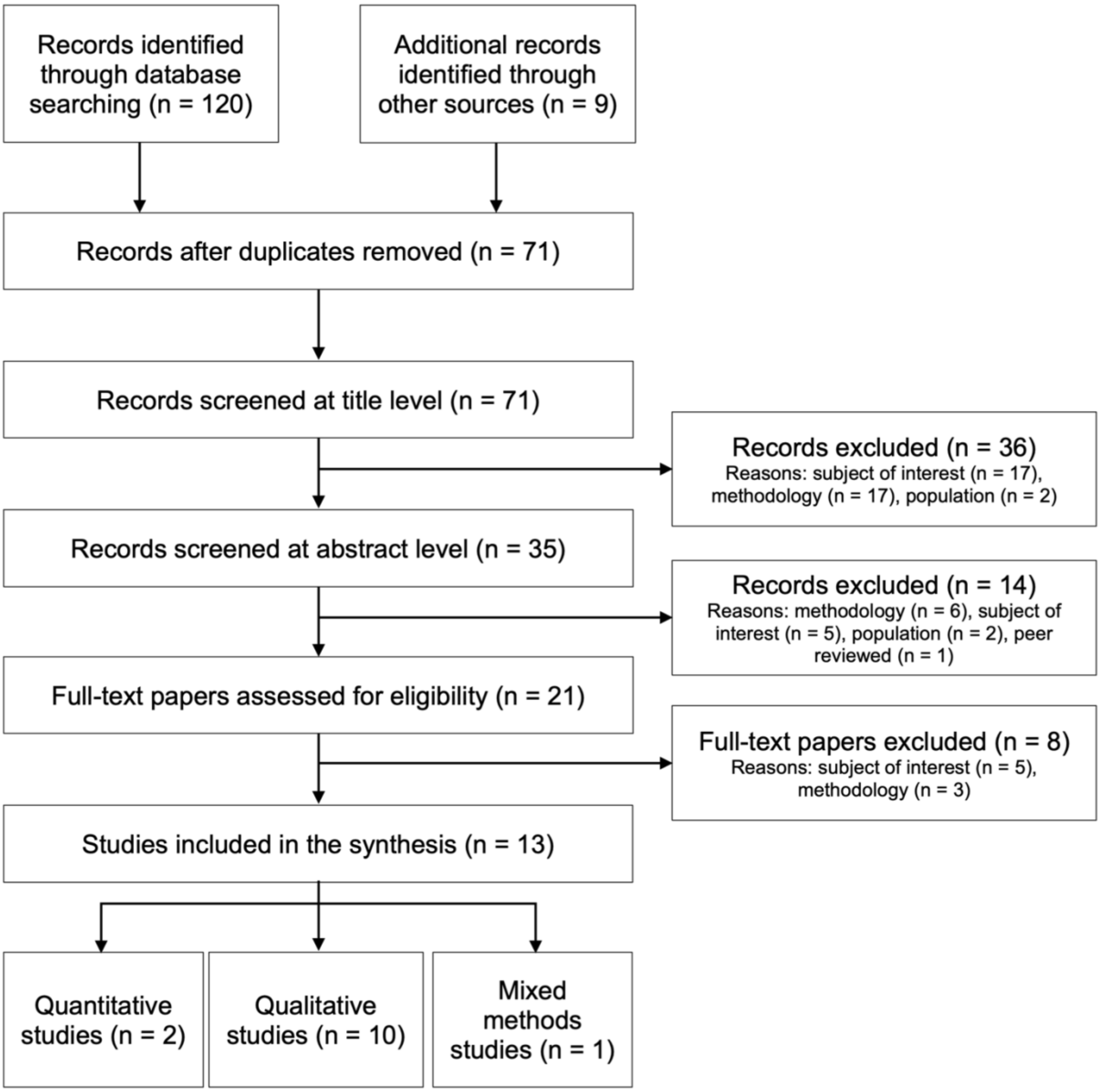
Appendices

Appendix A. Literature Review Search Strategy Flow Chart



Appendix B. Full Text Articles Assessed for Inclusion Eligibility

Number	Article Title	Author (Year)	Source	Rationale
1	‘Sometimes it feels as if the world goes on without me’: Adolescents' experiences of living with chronic fatigue syndrome.	Winger et al. (2014)	Database search	Meets the inclusion criteria
2	Adolescents and mothers value referral to a specialist service for chronic fatigue syndrome or myalgic encephalopathy (CFS/ME).	Beasant et al. (2014)	Database search	Topic - not focused upon school experiences (more focused on specialist healthcare)
3	Development of a conceptual framework to underpin a health-related quality of life outcome measure in paediatric chronic fatigue syndrome/myalgic encephalopathy (CFS/ME): Prioritisation through card ranking.	Parslow et al. (2020)	Database search	Meets the inclusion criteria
4	Health-related quality of life in Norwegian adolescents living with chronic fatigue syndrome.	Similä et al. (2021)	Database search	Meets the inclusion criteria
5	Important factors to consider when treating children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): perspectives of health professionals from specialist services.	Parslow et al. (2017)	Database search	Meets the inclusion criteria

6	"it's a medical condition … you need to support as much as possible": a qualitative analysis of teachers' experiences of chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME).	Brigden et al. (2021)	Database search	Meets the inclusion criteria
7	Long Term Follow up of Young People With Chronic Fatigue Syndrome Attending a Pediatric Outpatient Service.	Rowe (2019)	Database search	Methodology and Topic - no exploration of subjective experiences of school/education
8	Paediatric patients with myalgic encephalomyelitis/chronic fatigue syndrome value understanding and help to move on with their lives.	Rowe (2020)	Database search	Topic - limited exploration of school-related experiences due to focus on feedback regarding management plans.
9	School Functioning in Adolescents With Chronic Fatigue Syndrome.	Knight et al. (2018)	Database search	Meets the inclusion criteria
10	The importance of school in the management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Issues identified by adolescents and their families.	Clery et al. (2022)	Database search	Meets the inclusion criteria
11	A narrative inquiry into the school experiences of teenagers living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)	Lewis (2022)	Ethos	Meets the inclusion criteria

12	The secondary school experience with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) : an Interpretative Phenomenological Analysis of the retrospective accounts of young adults	Davies (2021)	Ethos	Meets the inclusion criteria
13	“The child’s got a complete circle around him”. The care of younger children (5–11 years) with CFS/ME. A qualitative study comparing families’, teachers’ and clinicians’ perspectives’	Brigden et al. (2020)	Snowballing	Meets the inclusion criteria
14	Psychological and demographic factors associated with fatigue and social adjustment in young people with severe chronic fatigue syndrome/myalgic encephalomyelitis: a preliminary mixed-methods study	Ali et al. (2019)	Google scholar	Meets the inclusion criteria
15	Chronic fatigue syndrome/myalgic encephalomyelitis in children aged 5 to 11 years: A qualitative study	Brigden (2020)	Google scholar	Topic - limited exploration of school-related experiences due to medical focus
16	Factors related to educational adaptations and social life at school experienced by young people with CFS/ME: a qualitative study	Similä et al. (2021)	Snowballing	Meets the inclusion criteria

17	Assessing functioning in adolescents with chronic fatigue syndrome: Psychometric properties and factor structure of the School and Social Adjustment Scale and the Physical Functioning Subscale of the SF36.	Loades et al. (2020)	Database search	Topic/Methodology - the study focused upon psychometric properties and factor structure of the measures used rather than CYP's experiences
18	Chronic fatigue syndrome in Chinese middle-school students.	Shi et al. (2018)	Database search	Methodology - no subjective components to explore experiences
19	Health related quality of life in adolescents with chronic fatigue syndrome: a cross-sectional study.	Winger et al. (2015)	Database search	Topic - insufficient exploration of school experiences
20	Severe myalgic encephalomyelitis/chronic fatigue syndrome in children and young people: a British Paediatric Surveillance Unit study.	Royston et al. (2023)	Database search	Methodology - no subjective components to explore experiences
21	Experiences Among School Personnel and School Nurses on Educational Adaptations for Students With CFS/ME: A Qualitative Interview Study	Similä et al. (2021)	Snowballing	Meets the inclusion criteria

Appendix C. Overview of Articles Included in the Literature Review

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Winger et al. (2014): ‘Sometimes it feels as if the world goes on without me’: Adolescents' experiences of living with chronic fatigue syndrome.	Norway	Experiences of ME/CFS	18 adolescents with ME/CFS	Sample recruited from wider cross-sectional research project (NorCAPITAL)	Qualitative design Data collection: Semi-structured interviews Data analysis: Phenomenological hermeneutical analytical approach (Lindseth & Norberg, 2004)	CYP with ME/CFS felt isolated from peers and limited by their illness, which affected their identity and personal freedom. The condition's invisibility often led to misunderstanding and emotional strain. Despite these challenges, they maintained hope for recovery and valued social and educational experiences.
Parslow et al. (2020): Development of a conceptual framework to underpin a health-related quality of life outcome measure in paediatric chronic fatigue syndrome/myalgic encephalopathy (CFS/ME): Prioritisation through card ranking.	UK	Experiences of ME/CFS and important outcomes	Multi-perspective: 21 adolescents and 22 parents	Sample recruited as part of a larger qualitative study, via outpatient clinics in a specialist service in South West England. Maximum variation purposive sampling used to recruit a range of participants.	Qualitative design Data collection: Semi-structured interview utilising a card ranking approach Data analysis: Thematic framework analysis	Adolescents with ME/CFS prioritised school alongside symptoms, facing academic challenges like reduced attendance, cognitive fatigue, and difficulties with concentration. Psychological wellbeing, including low mood and anxiety, was impacted. Contrastingly, parents viewed health as a higher priority than school.

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Similä et al. (2020): Health-related quality of life in Norwegian adolescents living with chronic fatigue syndrome.	Norway	Experiences of ME/CFS	63 adolescents with ME/CFS	Sample recruited through a hospital.	Quantitative, cross-sectional design Data collection: Questionnaire and brief structured interview Data analysis: Statistical analysis (Descriptive statistics, correlational analysis, two-sided independent sample t-tests, multiple linear regression model)	HRQoL in adolescents with ME/CFS was low, with higher levels linked to school attendance, teacher support, and leisure activities. Conversely, delayed school progression, depressive symptoms, and inpatient stays were associated with poorer outcomes. Most adolescents (76%) experienced delayed school progression, and 66% did not participate in leisure activities.
Parslow et al. (2017): Important factors to consider when treating children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): perspectives of health professionals from specialist services.	UK	Health professionals' perspectives on important factors for CYP with ME/CFS	15 healthcare professionals	Convenience sampling of health professionals through a gatekeeper (lead clinician) from a purposive sample of specialist paediatric ME/CFS services within the NHS, located in the South West, London, East of England and the North East.	Qualitative design Data collection: Focus groups and interviews (paired and individual) Data analysis: Thematic analysis (Braun & Clarke, 2006)	Healthcare professionals highlighted the following important outcomes: 1) symptoms; 2) physical function; 3) participation (school, activities and social life); and 4) emotional wellbeing. They also described the complexity of the condition, contextual factors and considerations for treatment to help children to cope with the condition.

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Brigden et al. (2021): "it's a medical condition … you need to support as much as possible": a qualitative analysis of teachers' experiences of chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME).	UK	Teacher's view and experiences of supporting pupils with ME/CFS	11 primary school staff members (based in the South West of England)	Families recruited via a specialist ME/CFS service in the South West of England. Teachers were invited to participate in interviews.	Qualitative design Data collection: Semi-structured interviews Data analysis: Thematic analysis (Braun & Clarke, 2014)	Teachers described ME/CFS as causing significant cognitive and physical challenges, with ripple effects on social, emotional, and academic functioning. Most tailored support to pupils' individual needs but time pressures and unpredictable attendance posed challenges. Two teachers expressed scepticism, leading to limited adaptations. Many teachers lacked knowledge of ME/CFS and called for more resources to better support affected pupils.
Knight et al. (2018): School Functioning in Adolescents With Chronic Fatigue Syndrome.	Australia	School experiences and support for adolescents with ME/CFS	67 adolescents (39 with ME/CFS, 28 healthy controls)	Recruitment through a hospital, convenience sampling. Participants with permanent school absence or home schooling, and those with severe cognitive impairment or learning disabilities were excluded.	Quantitative, cross-sectional design Data collection: Parent questionnaire (demographics and background information), Adolescent questionnaire and cognitive abilities and curriculum-based assessment. Data analysis: Statistical analysis (including chi-square, Mann-Whitney U, independent samples t-test, linear regression analyses).	Adolescents with ME/CFS experienced significantly higher school absence, poorer school-related quality of life, reduced participation, weaker school connectedness, and lower academic performance compared to their healthy peers. Fatigue severity and emotional symptoms were strongly associated with these challenges.

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Clery et al. (2022): The importance of school in the management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Issues identified by adolescents and their families.	UK	School experiences and support for adolescents with ME/CFS	Multi-perspective: 15 adolescents with ME/CFS, 16 family members, 10 medical professionals	The study combined data from two independent studies. Both studies recruited participants from one UK specialist paediatric ME/CFS service and professionals from the same region, using convenience sampling. Adolescents with severe ME/CFS were excluded from both studies.	Qualitative design, data drawn from two studies Data collection: Dataset was created from collating data from two previous studies, extracting data which pertained to schools. Semi-structured interviews and focus groups were used in these studies. Data analysis: Thematic analysis (Braun & Clarke, 2006).	School was viewed as crucial for CYP with ME/CFS, with stress around missing school affecting social and emotional wellbeing, and concerns about future opportunities. Families described varying levels of support and barriers such as disbelief and prioritisation of attendance over wellbeing. Three-way communication between families, schools, and health services, as well as increased awareness of ME/CFS, were highlighted as essential to better support.
Lewis (2022): A narrative inquiry into the school experiences of teenagers living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)	UK	School experiences and support for adolescents with ME/CFS (THESIS)	3 adolescents with ME/CFS	Recruitment via social media and EPs. Significant challenges encountered in recruitment.	Thesis. Qualitative design, Narrative approach. Data collection: Audio and written diaries Data analysis: Narrative analysis using the Listening Guide (Gilligan, 2015)	CYP with ME/CFS described physical and cognitive difficulties. They shared narratives of loss, including to academic, social, and autonomy. Experiences of misunderstanding, disbelief and disempowerment were described. Positive relationships with compassionate adults improved school engagement, while peer misunderstandings contributed to loneliness. They called for a shift from a diagnosis-dependent model to a needs-based approach and emphasised the importance of person-centred support and collaboration between schools and healthcare.

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Davies (2021): The secondary school experience with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) : an Interpretative Phenomenological Analysis of the retrospective accounts of young adults	UK	School experiences and support for adolescents with ME/CFS (THESIS)	2 young adults	Purposive sampling. Significant challenges encountered in recruitment.	Thesis. Qualitative design, IPA approach. Data collection: Semi-structured interviews gathered retrospective accounts Data analysis: IPA	CYP with ME/CFS faced challenges with physical needs, social exclusion, and emotional strain in school. Communication gaps and inconsistent support from staff impacted their experience, as did missed lessons and the inflexibility of school systems around curriculum demands like GCSEs. Home tuition was viewed positively for better adaptability to their needs.
Brigden et al. (2020): “The child’s got a complete circle around him”. The care of younger children (5–11 years) with CFS/ME. A qualitative study comparing families’, teachers’ and clinicians’ perspectives’	UK	Integration of care between health, school and home for 5–11-year-olds with ME/CFS	Multi-perspective: 8 primary-aged CYP with ME/CFS, 14 parents, 11 school staff, 9 clinicians	Sample recruited through two larger studies (EXPLORER and MAGENTA), which recruited from one specialist paediatric ME/CFS service in the South West of England.	Qualitative Data collection: Semi-structured interviews (6 of 8 children were interviewed in parent-child dyads) Data analysis: Thematic analysis (Braun & Clarke, 2006)	Young children with ME/CFS rely heavily on adult support, as they often struggle to regulate behaviour to manage their energy. Teachers, parents, and clinicians emphasised the importance of child-centred care, with distinct roles for each part of their systems. Communication and integrated care between health, education, and home were deemed vital but often limited by resource pressures and disbelief. Participants called for improved joint working and resources to enhance school knowledge and support for pupils with ME/CFS.

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Ali et al. (2019): Psychological and demographic factors associated with fatigue and social adjustment in young people with severe chronic fatigue syndrome/myalgic encephalomyelitis: a preliminary mixed-methods study	UK	Experiences of severe ME/CFS	51 CYP with severe ME/CFS	Recruitment through a charity for young people with ME/CFS.	Mixed-methods, short-term prospective design Data collection: Questionnaire administered at two time points, including open and closed questions and validated measures. Data analysis: Statistical analysis (included descriptive statistics, correlational analysis, and multiple regression analysis) and conventional content analysis (Hsieh & Shannon, 2005) for qualitative data.	ME/CFS negatively impacted many aspects of CYP's lives, including school attendance and social adjustment. Female gender and having accessed treatment were associated with lower school attendance. A lack of awareness about ME/CFS amongst others and resulting stigma was widespread.
Similä et al. (2021): Factors related to educational adaptations and social life at school experienced by young people with CFS/ME: a qualitative study	Norway	School experiences and support for adolescents with ME/CFS	18 young people aged 13-21	Sample recruited by mail for this study and a preceding study related to health-related quality of life.	Qualitative design Data collection: Semi-structured interviews Data analysis: Grounded theory	CYP raised concerns about insufficient school adaptations. Good communication and tailored support were associated with better educational and social experiences. Challenges included disbelief from teachers and reduced peer interaction. Online teaching during the Covid-19 pandemic was valued for improving social connection and equal access.

Author (Year): Title	Country	Focus	Participants	Sampling/ Recruitment	Research Design and Method	Findings
Similä et al. (2021): Experiences Among School Personnel and School Nurses on Educational Adaptations for Students With CFS/ME: A Qualitative Interview Study	Norway	School staff's experiences of providing adaptations for CYP with ME/CFS	6 teachers, 2 school counsellors, and 4 school nurses in secondary and high schools	Schools (n=18) and school nurses invited to participate via email (selected to be geographically distributed).	Qualitative design Data collection: Focus group (2) and interviews (remaining pps) - researchers planned focus groups but had to shift to individual interviews due to Covid-19 pandemic restrictions. Data analysis: Malterud’s Systematic Text Condensation, based on Giorgi's psychological phenomenological analysis.	Educational adaptations before diagnosis were challenging due to diagnostic delays, lack of teacher knowledge, and misjudged levels of support, impacting access to education and social contact. Students often lost confidence due to delegitimisation and unrealistic expectations. Collaboration with health professionals was valuable but hindered by conflicts between systems and resource pressures. Suggestions included early EPS involvement, digital teaching, improved teacher education, and sharing best practices across schools.

Appendix D. Critical Appraisal of Studies Included in the Literature Review

Table D1

CASP Qualitative Research Critical Appraisal 1

Question	Winger et al. (2014)	Parslow et al. (2020)	Parslow et al. (2017)	Brigden et al. (2021)	Clery et al. (2022)
1) Was there a clear statement of the aims of the research?	Yes, to explore the experiences of living with CFS during adolescence.	Yes, to understand what is most important to include in a conceptual framework related to health-related quality of life to underpin a new paediatric CFS/ME patient-reported outcome measure.	Yes, to explore the views and experiences of specialist paediatric CFS/ME health professionals and identify clinically important outcomes.	Yes, to explore teachers' views about ME/CFS, their experiences of supporting a pupil with CFS/ME and their perspectives on the barriers and facilitators to providing support. This was considered important to understand children's needs in a school setting and common barriers and facilitators to teachers' offering support.	To some extent as it aimed to demonstrate the importance of education and explore how adolescents with ME/CFS can be better supported in school. However, the paper was incidental, arising out of interviews conducted as part of 2 separate studies, therefore interviews were not conducted with the aims of this paper in mind.
2) Is a qualitative methodology appropriate?	Yes, due to exploratory purpose.	Yes, the authors wanted to gather enough detail about priorities and experiences to develop questionnaire items and the qualitative design supports this.	Yes, qualitative methodology appropriate for exploring experiences and perspectives.	Yes, as the research sought to explore subjective views related to the experience of supporting pupils with ME/CFS.	Yes, for exploring experiences and perspectives.

Question	Winger et al. (2014)	Parslow et al. (2020)	Parslow et al. (2017)	Brigden et al. (2021)	Clery et al. (2022)
3) Was the research design appropriate to address the aims of the research?	Yes, qualitative design with in-depth interviews with adolescents with CFS facilitated exploration of their experiences.	Yes, the card ranking with interviews to probe reasons was considered appropriate to support prioritisation of outcomes and develop greater understanding about these concepts.	Yes, research with relevant health professionals from specialist paediatric CFS/ME services across the UK was appropriate to explore their perspectives.	Yes, qualitative interviews were appropriate to explore teachers' experiences. These were conducted as part of a larger longitudinal cohort study. The qualitative element had originally intended to explore experiences of families and children, however early findings indicated a need for exploration of teacher views, which resulted in the current research.	To some extent. The paper is based upon data from two separate studies which were not designed with the aims of the present paper in mind (they were focused on access to treatment for adolescents from ethnic minority backgrounds, and Acceptance and Commitment Therapy). Nevertheless, the qualitative multi-perspective design is appropriate to address the current aim.
4) Was the recruitment strategy appropriate to the aims of the research?	Yes. Participants were recruited consecutively from a wider cross-sectional research project (NorCAPITAL) which focused on disease mechanisms, treatment effects and patient experiences in adolescence.	Yes. Families (adolescents and their parents) were recruited from outpatient clinics, all from one specialist paediatric chronic fatigue service in South West England. Maximum variation purposive sampling was used to support researchers to recruit a diverse range of participants. However, adolescents with	Yes, researchers purposively sampled specialist paediatric CFS/ME services from across the UK. Authors note that although they intended sampling to be purposeful, reliance on access via a gatekeeper (lead clinician) resulted in a convenience sample. This remained	Yes. Teachers were recruited through families of pupils aged 5-11 who attended a specialist ME/CFS service in the South West of England. Purposive sampling was used to ensure diversity in relation to pupil age and school attendance levels. Recruitment continued until pragmatic	The study combined data from two independent studies. Both studies recruited participants from one UK specialist paediatric ME/CFS service and professionals from the same region, using convenience sampling. Adolescents with severe ME/CFS were excluded from both studies.

Question	Winger et al. (2014)	Parslow et al. (2020)	Parslow et al. (2017)	Brigden et al. (2021)	Clery et al. (2022)
		moderate CFS/ME were under-represented in the sample, and severe cases were excluded. Further, experiences may not represent those elsewhere in the country (e.g. in areas without a specialist CFS/ME service).	appropriate for the study, although some people chose not to take part due to time issues. Sampling bias may affect findings.	saturation. Schools were asked to identify an appropriate staff member to participate and so this self-selection may have resulted in sampling bias.	
5) Was the data collected in a way that addressed the research issue?	Yes, in-depth interviews enabled adolescents to speak freely and share their experiences through narratives.	Yes, semi-structured interview utilising a card ranking approach were conducted with adolescents and their parents separately. The card-ranking exercise was considered an innovative, interactive, child-friendly technique to explore experiences, and which reduced interviewer effects due to adolescents being in control of ranking outcomes. However, in 4 adolescent interviews, their parents were present which may have influenced social desirability of responses. Three interview transcripts were	Yes. Focus groups and interviews (individual and paired) were used to gather detailed contributions. Focus groups were conducted where possible to facilitate group interaction and breadth of discussion, although interviews were offered where this was not possible. The authors acknowledge that different forms of data collection can lead to different data being generated, although they considered all methods appropriate for the study and wanted to enhance	Yes. Semi-structured interviews utilised a topic guide which was based upon evidence relating to the management of chronic health conditions within schools as well as research aims. Participants were invited to add anything that had not been covered by questions in the interview to capture a broad range of views and experiences. Topic guides were reviewed to encourage exploration of challenges to get a balanced view.	To some extent. Data was collected through semi-structured interviews for the majority of participants and focus groups for medical professionals in study 2. Topic guides were developed for each participant group; however, these were not designed with the aims of the present study (focused on school) in mind. Some interviews were conducted with parent-child dyads, whilst others were separate. The different data collection approaches are likely to have influenced upon the

Question	Winger et al. (2014)	Parslow et al. (2020)	Parslow et al. (2017)	Brigden et al. (2021)	Clery et al. (2022)
		reviewed in a multi-disciplinary meeting for quality assurance.	participant engagement.		nature of data. Further, interviews may have been influenced by parent-child dynamics and greater weight may have been given to parents' voices.
6) Has the relationship between researcher and participants been adequately considered?	No	No. Researchers clarified to participants that they were not part of the clinical team to limit the influence of their role in participants' responses, although no further reflection was provided.	No. One researcher facilitated the focus groups and conducted all interviews. Their relationship with participants is not considered, although authors note that the topic guide was revised throughout the study to reflect emerging issues.	No. Researchers clarified to participants that their roles were as researchers, not clinicians, however no further considerations were reflected upon within the paper.	No.
7) Have ethical issues been taken into consideration?	Yes. The study received ethical approval from the Norwegian Social Science Data Service and Norwegian Regional Committee for Ethics in Medical Research. Informed consent and the right to withdraw was considered,	Yes, written consent was obtained from both parents and adolescents and participants were offered choice over interview location to suit individual needs. Full ethical approval was obtained from the NRES Committee North West.	Somewhat. Consent was obtained from participants. The study was approved by the University of Bristol's Faculty of Medicine and Dentistry Committee for Ethics and relevant research and development approval was obtained for each site.	Yes. Informed consent was obtained from both families and teachers, and children were also involved in recruitment discussions to ensure that they were willing to take part. Participant information sheets and consent/assent procedures were co-	Ethical approval was obtained. Informed consent was obtained for all participants.

Question	Winger et al. (2014)	Parslow et al. (2020)	Parslow et al. (2017)	Brigden et al. (2021)	Clery et al. (2022)
	alongside opportunity for breaks during interviews.			constructed with a young person advisory group. Ethical approval was obtained.	
8) Was the data analysis sufficiently rigorous?	Yes. The authors followed a phenomenological hermeneutical approach (Lindseth & Norberg, 2004) to analyse life-world experiences. This involved a thorough process of naïve reading, thematic structural analysis, and comprehensive understanding.	Yes, thematic framework analysis was used, coding the data deductively and then inductively. Analysis utilised NVivo. Ten transcripts were double coded and reviewed to ensure trustworthiness of analysis.	Yes, thematic analysis (Braun & Clarke, 2006) was used to analyse findings, using both deductive and inductive coding. The software package NVivo 10 was used for coding. Other members of the research team read and independently coded a subset of data.	Yes, thematic analysis (Braun & Clarke, 2014) was used. Codes were inductive and iteratively developed as analysis progressed. An independent coder reviewed coding of a subset of the data and contributed to interpretation of findings and write up of the themes.	Yes, thematic analysis (Braun & Clarke, 2006) was used to inductively code data, using NVivo. Transcripts were double coded for both independent studies which led to the identification of overlapping themes about schools. This led to the creation of a new dataset, collating data from both studies which pertained to schools. Illustrative quotes for themes and sub-themes were included within write up.
9) Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes.

Question	Winger et al. (2014)	Parslow et al. (2020)	Parslow et al. (2017)	Brigden et al. (2021)	Clery et al. (2022)
10) How valuable is the research?	Comprehensive insight into adolescent experiences of CFS, particularly focused on social experiences (with just a small focus on school/educational experiences). Suggests implications for healthcare professionals.	The study elicited the most important outcomes to adolescents with ME/CFS and their parents, with added qualitative exploration of how these impacted upon children and young people. This supported the development of a conceptual framework for health-related quality of life in ME/CFS which could be used as a patient-reported outcome measure.	The study made a novel contribution as the second study in this area to explore perspectives of health professionals. Clinically important outcomes for health professionals to consider arose out of the research which correspond with the wider evidence base, and authors suggest the development of a patient reported outcome measure based on these findings.	The study contributed a novel contribution exploring teacher views and focusing upon the primary phase.	This study provides a multi-perspective view on the strengths and tensions in relation to the experience of CYP with ME/CFS in engaging with secondary education. However, as interviews were not designed for the purpose of research exploring school experiences, there may be further parts of the story that were not captured within this research.

Table D2

CASP Qualitative Research Critical Appraisal 2

Question	Lewis (2022)	Davies (2021)	Brigden et al. (2020)	Similä, Nøst, et al. (2021)	Similä, Rø, et al. (2021)
1) Was there a clear statement of the aims of the research?	Yes, to explore the school experiences of young people with ME/CFS, currently on roll in a mainstream setting using a narrative approach.	Yes, to explore how young adults who had a diagnosis of CFS/ME while at secondary school describe and perceive their experiences of education with the illness.	Yes, to examine the extent to which care of younger children with ME/CFS is integrated across settings.	Yes, to explore factors perceived as positive or negative among young people with CFS/ME in relation to school and everyday life. After the Covid-19 pandemic, supplementary interviews were conducted to explore an additional area, relating to perceptions of the switch to online schooling and altered contact with school following the COVID-19 pandemic.	Yes, to explore teachers, counsellors, and school nurses' experiences with adaptations of education for students with ME/CFS aged 13–19 in secondary and high school. This followed limited research exploring how schools adapted education for students with ME/CFS.
2) Is a qualitative methodology appropriate?	Yes, to facilitate in-depth exploration of experiences.	Yes, to explore young people's experiences.	Yes, to explore perspectives.	Yes, to explore views and experiences.	Yes, because the study aimed to explore lived experiences.
3) Was the research design appropriate to address the aims of the research?	Yes, narrative inquiry was appropriate to explore how individuals made sense of how ME/CFS shaped experiences of learning and education.	Yes, an IPA approach was used to explore individual experiences.	Yes, a multi-perspective qualitative design supported exploration of perspectives of families, teachers, and clinicians.	Yes, semi-structured interviews with young people supported exploration of their experiences.	Yes, qualitative focus groups and interviews facilitated in-depth exploration of staff's experiences of supporting CYP with ME/CFS in school.

Question	Lewis (2022)	Davies (2021)	Brigden et al. (2020)	Similä, Nøst, et al. (2021)	Similä, Rø, et al. (2021)
4) Was the recruitment strategy appropriate to the aims of the research?	Yes, participants aged 13-18 who were enrolled in a mainstream school and had ME/CFS were recruited through social media (an appropriate channel for accessing this age group) and through EPs. The author encountered recruitment challenges which resulted in a small sample size, although this remained appropriate for the narrative approach and the aim of exploring individual narratives.	To some extent. Purposive sampling aimed to recruit 3-6 participants aged 18-25 who had a diagnosis of ME/CFS at secondary school. However, recruitment challenges meant that only 2 participants were recruited for the study.	Yes. Participants were sampled from two large-scale studies (EXPLORER and MAGENTA) which encompassed qualitative interviews, conducted at a large specialist paediatric ME/CFS service. Children aged 5-11 and their parent/carers were purposefully sampled from both studies to ensure diversity in the sample. Clinicians were purposefully sampled, recruited from the EXPLORER study. School staff were later included in the study following early analysis; they were purposefully sampled, recruited following consent from families in the EXPLORER study. Interviews continued until data reached saturation.	Yes. Participants were recruited from two university hospitals with specialist CFS/ME assessment services, recruited by mail for this study and a preceding health-related quality of life study. It is noted that initial interviews took place prior to the Covid-19 pandemic, and so supplementary interviews were conducted with 16 of the 18 participants in September 2020 to explore perceptions about the move to online schooling.	Yes, schools and school nurses were invited to participate via email. Schools contacted were geographically distributed to ensure representation from urban and rural districts. All participants who expressed interest were invited to participate. Less participants were recruited than intended (12 pps, compared with aim of 24-32 pps in focus groups) - this may have been due to the change in data collection approach to interviews due to the covid-19 pandemic, however, isn't explicitly explained. The exact sampling strategy (e.g. convenience/purposive sampling) was not explicitly stated - it is unclear how the schools approached were selected beyond being geographically distributed.

Question	Lewis (2022)	Davies (2021)	Brigden et al. (2020)	Similä, Nøst, et al. (2021)	Similä, Rø, et al. (2021)
5) Was the data collected in a way that addressed the research issue?	Yes. Diaries were selected as a data collection method to obtain an in-depth understanding of participants' lived experiences in a way that was participant-led and mitigated common barriers to research participation for CYP with ME/CFS linked with energy impairment in interviews.	Yes, semi-structured interviews were used to facilitate in-depth exploration of experiences using an individualised approach which is appropriate for IPA and the research questions.	Yes. Face to face, semi-structured interviews were conducted. Separate topic guides were developed for each participant group, based on evidence, research aims, and consultation with two patient and public advisory groups. The majority of children (6 out of 8) were interviewed in their parent-child dyad, which may have influenced social desirability and limited attention to child voice.	Yes. The interview guide was developed by a group of specialist health professionals based on previous knowledge about perceived challenges for CYP with CFS/ME.	Yes, focus groups and interviews are appropriate for exploring experiences. Focus groups were originally planned as the sole data collection method however disruption caused by the COVID-19 pandemic meant that researchers had to adapt in response to restrictions, leading to individual interviews.
6) Has the relationship between researcher and participants been adequately considered?	Yes. In line with narrative approaches, the author reflected on the importance of prolonged engagement, issues of power in participant-researcher relationships, and the influence of researcher's	Yes. The researcher reflected upon their own interests and motivations in the research area and the potential bias that may be associated with this. This was managed through explicit	Issues related to power imbalances in interviews were acknowledged and addressed by offering different interview locations to participants.	No. The paper notes that 3 participants had previously met the interviewer (a PhD student and specialised nurse) in a meeting or course at hospital. However, no further consideration regarding implications of this is provided.	Somewhat, the authors mention reflexivity in relation to their experience with CYP with ME/CFS, experience with qualitative methodologies, and use of two pedagogues inputting into design of interviewer guide to limit influence of authors’

Question	Lewis (2022)	Davies (2021)	Brigden et al. (2020)	Similä, Nøst, et al. (2021)	Similä, Rø, et al. (2021)
	perceptions and experience in analysis.	consideration of reflexivity and bracketing, for example by keeping a reflective journal and accessing supervision to support with interpretation of findings.			preconceptions on the guide. However, beyond stating this, they do not critically examine the influence of these factors/their role on the research.
7) Have ethical issues been taken into consideration?	Yes, ethical approval was obtained, informed consent was gathered, confidentiality and anonymity were ensured, and the researcher strived to minimise harms to participants and ensure that their involvement was meaningful and positive.	Yes. Ethical approval was obtained, informed consent was gathered, confidentiality and anonymity were ensured, and steps were taken to protect participants from potential harm, including related to symptoms related to ME/CFS.	Ethical approval was obtained. Written, informed consent/assent was obtained from parents and children, clinicians and school personnel.	Yes. Informed consent was gathered. Interview location was offered in participants' homes to reduce fatigue associated with travel. Interviewees could pause or stop interviews at any point and choose to have a parent with them if they wished.	Yes, the study stated that it received ethical approval and followed ethical standards. Ethical issues such as informed consent, anonymity in focus groups and write up, and data storage and handling were explicitly addressed.
8) Was the data analysis sufficiently rigorous?	Yes, narrative analysis following the Listening Guide (Gilligan, 2015) procedure which is considered to be well-suited for research	Yes, data analysis followed the IPA process.	Yes, thematic analysis (Braun & Clarke, 2006) was used. Datasets were initially analysed separately within participant	A grounded theory approach was applied.	Malterud's Systematic Text Condensation (STC), based on Giorgi's psychological phenomenological analysis, was used.

Question	Lewis (2022)	Davies (2021)	Brigden et al. (2020)	Similä, Nøst, et al. (2021)	Similä, Rø, et al. (2021)
	"involving marginalised experiences, including those involving social stigma" (Sorsoli & Tolman, 2008, p. 495).		groups, then compared and contrasted between groups. The authors state that interpretation of data was underpinned by socioecological theory.		Preliminary themes were discussed with a national interdisciplinary forum (experienced with CYP with ME/CFS) and a research group. The research describes each stage of analysis and presents evidence of this to enhance transparency and rigour.
9) Is there a clear statement of findings?	Yes. In line with narrative approaches, findings were presented separately for individual participants' narratives. Within the discussion, these were considered collectively in relation to each research question, drawing upon Bronfenbrenner's ecological systems theory (1979) and Ryan and Deci's Self-determination theory (2017) as explanatory frameworks.	Yes, themes are clearly stated. They are compared between participants and clearly described with reference to individual quotes as evidence. The discussion considered how themes addressed the research questions.	Yes	Yes	Yes

Question	Lewis (2022)	Davies (2021)	Brigden et al. (2020)	Similä, Nøst, et al. (2021)	Similä, Rø, et al. (2021)
10) How valuable is the research?	The research used a unique design and methodology to empower the voices of CYP with ME/CFS, an under-researched area. Findings informed development of a model for practice, draws implications for EP practice, and identifies areas for further research.	Yes, the research uniquely contributed retrospective accounts of YP's lived experiences of ME/CFS in education. Implications for professional practice and future research are drawn.	The multi-perspective research highlights aspects which are likely to influence the school experience of younger pupils with ME/CFS. Specifically, pupil-teacher relationships, and joint working between school, health, and home were seen to influence experiences of support for pupils.	The study provided novel and important findings regarding online teaching during the Covid-19 pandemic. It was also the first study to be conducted in Norway exploring perceived factors related to school functioning in CYP with CFS/ME.	The study contributes suggestions for successful educational adaptations for CYP with ME/CFS based upon school staff experiences.

Table D3

CEBMa Critical Appraisal of Surveys

Critical Appraisal Question	Similä et al. (2020)	Knight et al. (2018)
1. Did the study address a clearly focused question / issue?	Yes, the primary aim was to measure health related quality of life (HRQoL) in adolescents with ME/CFS. A secondary aim was to identify factors associated with HRQoL before diagnosis, at time of diagnosis and after diagnosis.	Yes, it compared school functioning between adolescents with CFS and healthy controls and the interaction between fatigue severity and emotional symptoms with school functioning in CFS.
2. Is the research method (study design) appropriate for answering the research question?	Yes, a cross-sectional, population-based study design was used to assess HRQoL. This was appropriate to explore HRQoL levels and factors associated with HRQoL at different time points.	Yes, the quantitative enabled comparisons and interactions between factors to be considered. However, a mixed-methods approach which incorporated qualitative elements may have facilitated a more in-depth exploration of school functioning and experiences.
3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?	Yes, adolescents diagnosed at a hospital were recruited via mail.	Yes, patients with CFS were recruited through one paediatric tertiary hospital. The control group were recruited through convenience sampling.
4. Could the way the sample was obtained introduce (selection)bias?	All adolescents who received diagnoses at the hospitals were invited to reduce bias, however the self-selecting nature and inclusion of just one chain of hospitals means that sampling bias is likely to be present to some extent. Further, only 48 responded to phone interviews, introducing a lost-to-follow-up bias.	Yes. The response rate was 50% and so sampling bias is likely to be present as factors related to health and interest in the area were reported to impact upon choices not to participate.
5. Was the sample of subjects representative with regard to the population to which the findings will be referred?	Can't tell, however the sample was relatively small which limits generalisability.	Not sure. The sample size was small, although there were no significant group differences on key demographic variables, beyond small but significant differences in age and intelligence.
6. Was the sample size based on pre-study considerations of statistical power?	Not mentioned.	Not mentioned.

Critical Appraisal Question	Similä et al. (2020)	Knight et al. (2018)
7. Was a satisfactory response rate achieved?	To some extent. 51.2% of participants invited agreed to participate and only 37.5% returned completed questionnaires. There is a risk of sampling bias related to non-responses.	To some extent. The response rate was 50%.
8. Are the measurements (questionnaires) likely to be valid and reliable?	Yes, validated measures were used (PedsQL generic core scale, PedsQL multidimensional fatigue scale, short mood and feelings questionnaire, De Paul pediatric health questionnaire – Norwegian version) in addition to medical records and 6–7-minute structured telephone interviews.	Yes, validated measures were used. However, issues related to intelligence testing must be considered when interpreting results (e.g. related to representativeness of standardisation samples and theories of intelligence).
9. Was the statistical significance assessed?	Yes	Yes
10. Are confidence intervals given for the main results?	Yes	Yes
11. Could there be confounding factors that haven't been accounted for?	Yes, other factors that might impact health-related quality of life, such as socioeconomic status.	Yes, other factors that might impact a child's school functioning e.g. socioeconomic status, SEND.
12. Can the results be applied to your organization?	The small sample size and different geographical location limit generalisability to the UK, however, the study contributes preliminary findings related to factors associated with HRQoL in adolescents with ME/CFS at different stages of the condition.	The small sample size and sampling method (i.e. adolescents from one hospital, sampling bias) limit generalisability. However, findings provide an important contribution to a preliminary understanding of school functioning. Further research is required to explore this.

Table D4

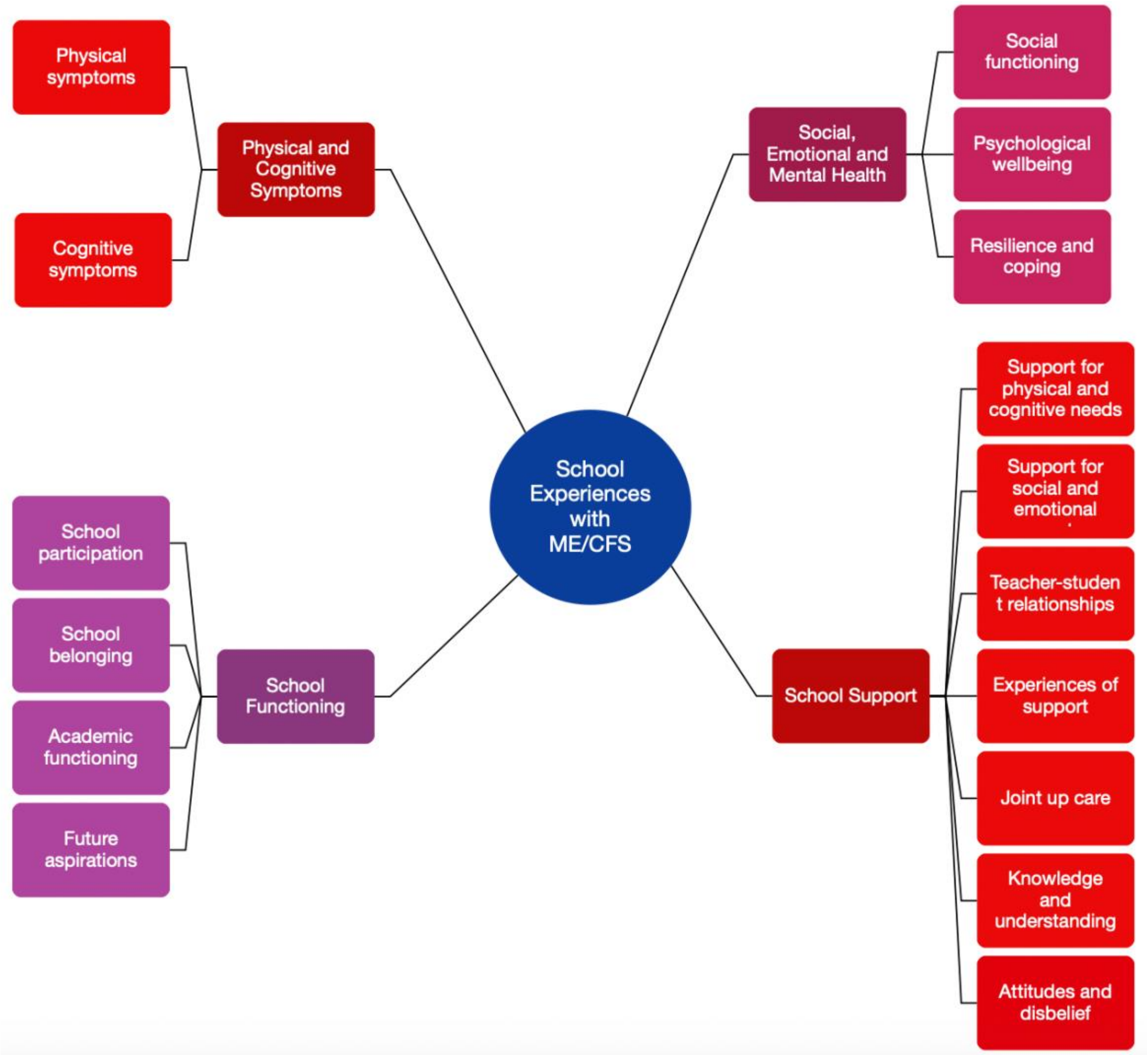
Mixed Methods Appraisal Tool (MMAT) Version 2018 Applied to Ali et al. (2019)

Category of study designs	Methodological quality criteria	Comments
Screening questions (for all types)	S1. Are there clear research questions?	Yes, two research questions: 1. Are factors such as fear avoidance, gender, age, and access to treatment associated with the key outcomes of fatigue, social adjustment and work/school attendance in young people with severe CFS/ME? 2. What are the lived experiences of young people with severe ME/CFS?
	S2. Do the collected data allow to address the research questions?	Yes, a survey collected both quantitative data (from validated tools) to assess the first research question, and qualitative data (from an open-ended question) to explore the second research question.
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	Yes, a qualitative design was appropriate for exploring experiences in greater depth.
	1.2. Are the qualitative data collection methods adequate to address the research question?	Somewhat. Use of open-ended questions in a questionnaire facilitates qualitative exploration of experiences across a relatively large sample, however responses often lack depth to provide rich, detailed responses about lived experiences.
	1.3. Are the findings adequately derived from the data?	Yes, conventional content analysis (Hsieh & Shannon, 2005) was used to inductively code data into categories and 6 overarching themes. Frequency of each category occurring was recorded.
	1.4. Is the interpretation of results sufficiently substantiated by data?	Yes, adequate quotations were included within write up to exemplify themes.
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes, there were clear links between the open-ended questionnaire, analysis of responses, and interpretation.

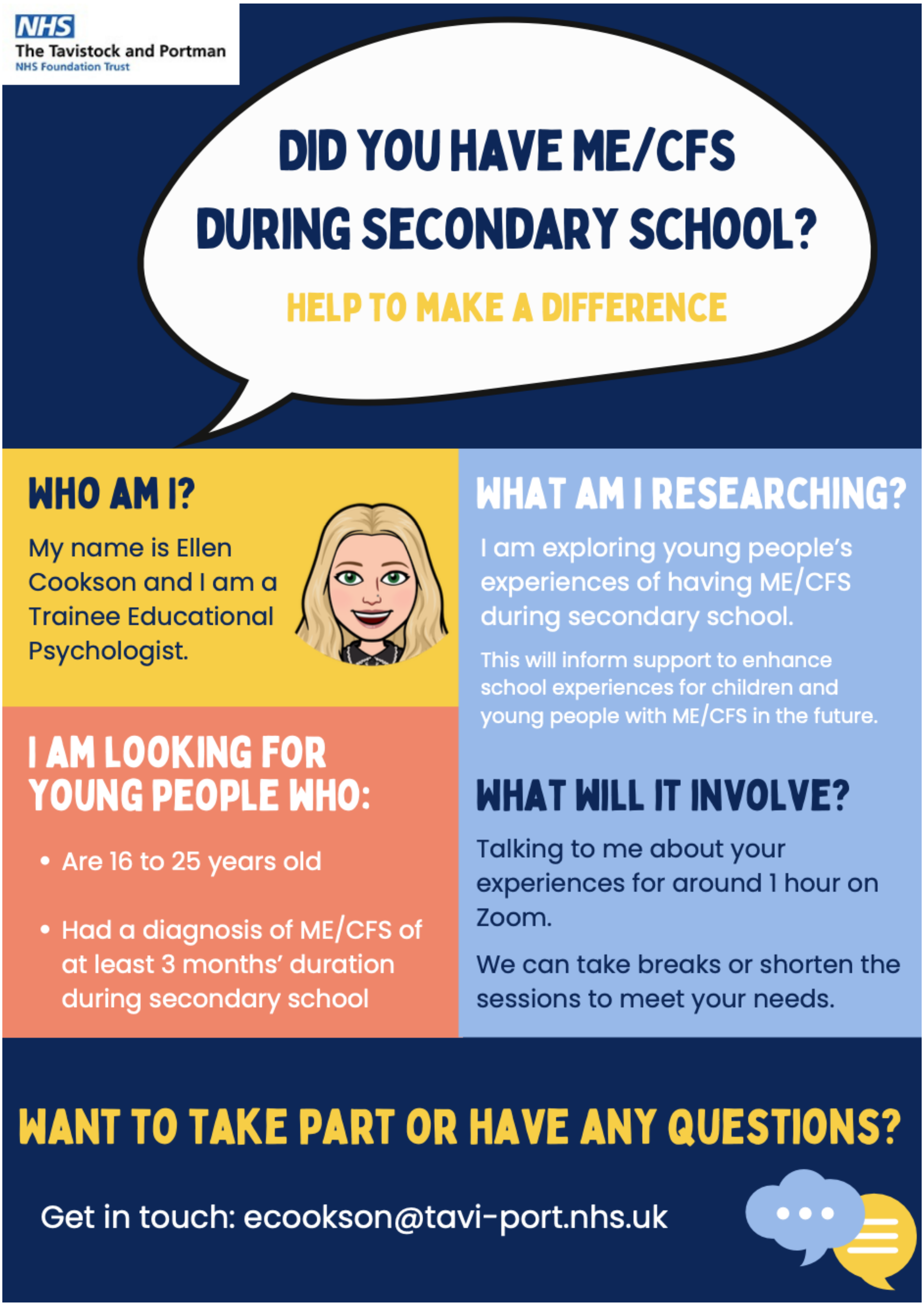
Category of study designs	Methodological quality criteria	Comments
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	Yes. Participants were recruited through a charity for young people with ME/CFS; letters were distributed to members and advertisements were placed on mailing lists and social media. Severe ME/CFS was assessed using a self-report rating scale. Inclusion criteria were broadened (upper age limit and ME/CFS severity) to increase recruitment rates.
	4.2. Is the sample representative of the target population?	No. The study has a small sample size and may not be representative of young people with severe ME/CFS in the general population.
	4.3. Are the measurements appropriate?	Yes. Validated measures were used to explore fatigue (Chalder fatigue scale), social adjustment (Work and Social Adjustment scale), fear avoidance beliefs (subscale of the Cognitive Behavioural Responses questionnaire), and presence of anxiety and depression (PHQ-2 and GAD-2).
	4.4. Is the risk of nonresponse bias low?	The authors did not report the response rate or reasons for non-response. However, inclusion criteria were expanded to increase recruitment rates which may indicate issues with responses, thus introducing the risk of nonresponse bias.
	4.5. Is the statistical analysis appropriate to answer the research question?	Yes. Descriptive statistics were used for baseline characteristics, correlations facilitated examination of relationships between variables at T1 and T2, and multiple regression analyses examined the association between factors in the research question with fatigue, social adjustment, and work/school attendance at T2.
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	Yes, to explore predictors of outcomes in young people with ME/CFS and explore lived experiences. Quantitative data was used to investigate the association between factors, whilst qualitative data was used to explore lived experiences.

Category of study designs	Methodological quality criteria	Comments
	5.2. Are the different components of the study effectively integrated to answer the research question?	The quantitative and qualitative elements of the study respond to different research questions and do not appear to have been integrated during analysis or interpretation.
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	No. During interpretation of findings, the authors miss an opportunity to integrate quantitative findings of factors related to social adjustment and school attendance with qualitative findings relating to experiences.
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Data was not integrated so it is unclear whether there were any divergences and inconsistencies.
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	To some extent.

Appendix E. Literature Review Thematic Map



Appendix F. Research Recruitment Poster



NHS
The Tavistock and Portman
NHS Foundation Trust

DID YOU HAVE ME/CFS DURING SECONDARY SCHOOL?

HELP TO MAKE A DIFFERENCE

WHO AM I?

My name is Ellen Cookson and I am a Trainee Educational Psychologist.

WHAT AM I RESEARCHING?

I am exploring young people's experiences of having ME/CFS during secondary school.

This will inform support to enhance school experiences for children and young people with ME/CFS in the future.

I AM LOOKING FOR YOUNG PEOPLE WHO:

- Are 16 to 25 years old
- Had a diagnosis of ME/CFS of at least 3 months' duration during secondary school

WHAT WILL IT INVOLVE?

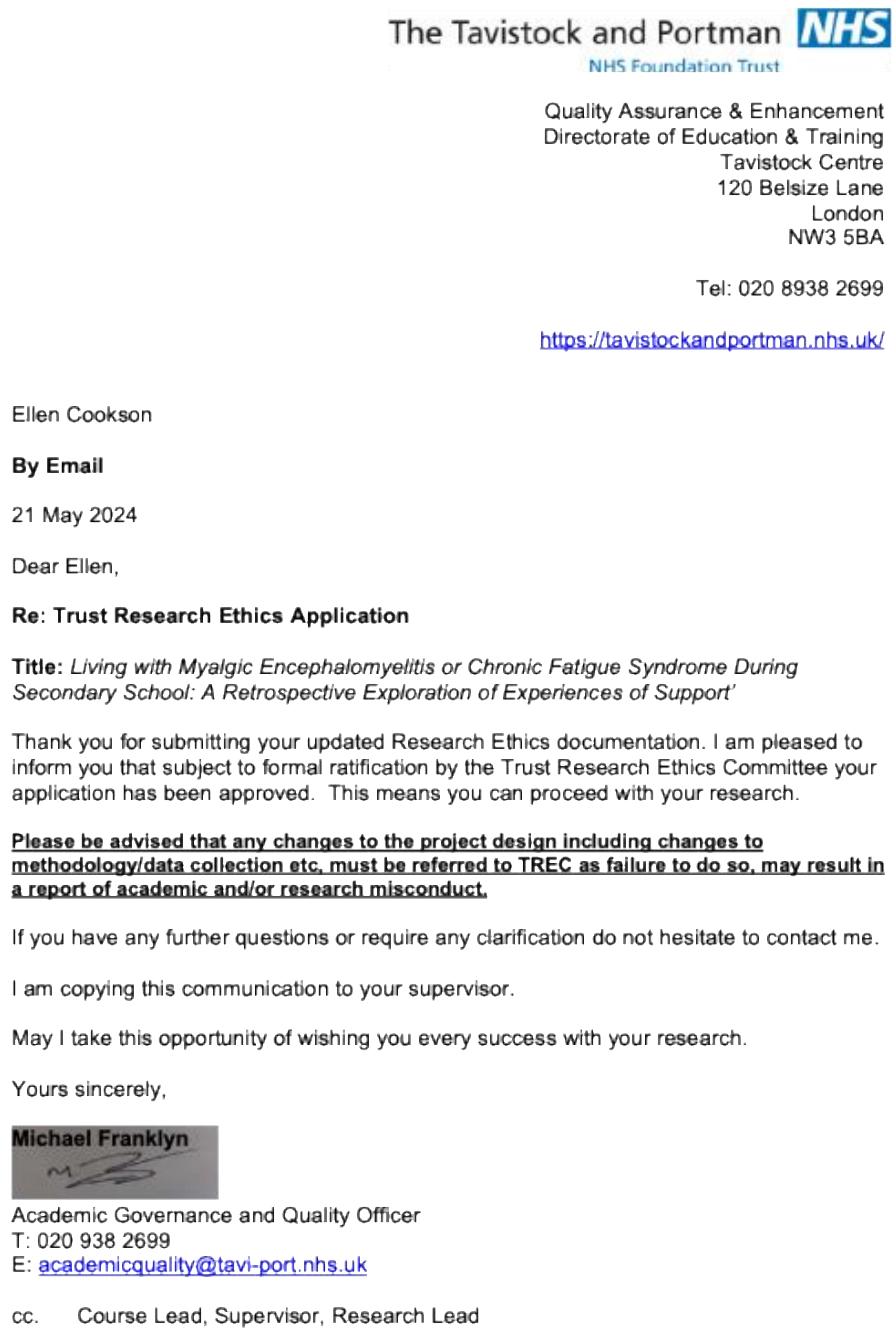
Talking to me about your experiences for around 1 hour on Zoom.

We can take breaks or shorten the sessions to meet your needs.

WANT TO TAKE PART OR HAVE ANY QUESTIONS?

Get in touch: ecookson@tavi-port.nhs.uk

Appendix G. TREC Ethical Confirmation and Approval of Amended Application



The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699

https://tavistockandportman.nhs.uk/

Ellen Cookson

By Email

21 May 2024

Dear Ellen,

Re: Trust Research Ethics Application

Title: *Living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome During Secondary School: A Retrospective Exploration of Experiences of Support'*

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

Please be advised that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

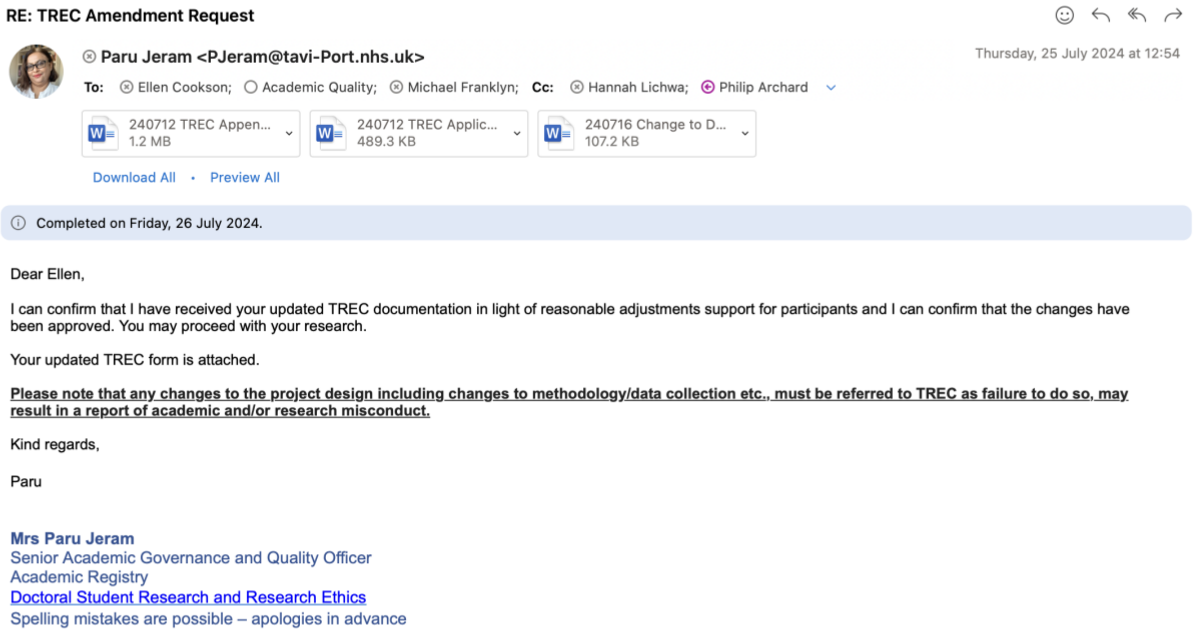
May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Michael Franklyn

Academic Governance and Quality Officer
T: 020 938 2699
E: academicquality@tavi-port.nhs.uk

cc. Course Lead, Supervisor, Research Lead



RE: TREC Amendment Request

Paru Jeram <PJeram@tavi-Port.nhs.uk>

Thursday, 25 July 2024 at 12:54

To: Ellen Cookson; Academic Quality; Michael Franklyn; **Cc:** Hannah Lichwa; Philip Archard

Completed on Friday, 26 July 2024.

Dear Ellen,

I can confirm that I have received your updated TREC documentation in light of reasonable adjustments support for participants and I can confirm that the changes have been approved. You may proceed with your research.

Your updated TREC form is attached.

Please note that any changes to the project design including changes to methodology/data collection etc., must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

Kind regards,

Paru

Mrs Paru Jeram
Senior Academic Governance and Quality Officer
Academic Registry
Doctoral Student Research and Research Ethics
Spelling mistakes are possible – apologies in advance

Appendix H. Participant Information Sheet

Participant Information Sheet

Living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome During Secondary School: a Retrospective Exploration of Experiences of Support

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Who is doing the research?
My name is Ellen Cookson, and I am studying a course in Educational Psychology. I am conducting this piece of research as part of the course.

What is the aim of the research?
The aim of this research is to explore your experience of living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) during secondary school and learn how educational professionals can support and enhance the educational experience and well-being of young people like yourself.

This research is important because it will help to improve knowledge and understanding amongst educational professionals and will support inclusive practice for children and young people with ME/CFS within schools.

Who can take part in this research?
I am looking for 16–25-year-olds who had a diagnosis of ME/CFS of at least 3 months' duration during their secondary education. You will **not** be expected to provide any proof of diagnosis to participate in this research.

The research will take place online (on Zoom) so you can take part if you live anywhere in the UK.

Do I have to take part?
You do not have to take part in this study. If you decide that you want to take part and then change your mind later, that's ok; you are free to stop taking part in this study at any point until 3 weeks after your interview. You do not need to give a reason if you decide not to take part.

Your involvement in this study will have no impact on your access to any support that you usually receive.

What is involved in the research?
- I will ask you to complete a consent form and return this to me via email.
- We will agree on a convenient time to meet on Zoom (any time between 8:30am-5pm, Monday-Friday). I will also ask you to share whether you require any reasonable adjustments to support your participation in the research.
- At the start of the meeting, I will tell you more about the research and answer any questions that you might have.
- I will then ask you some questions about your experience of having ME/CFS during secondary school. You may be asked to do a brief drawing or writing activity.
- If you would like to stop the interview at any point, you will be free to do so. You do not have to give a reason for this.

- At the end of the meeting, I will debrief with you and reflect on how you found the session.
- The whole meeting will last approximately 1 hour. We can split this over two shorter sessions if you would prefer.
- The meeting will be audio and video recorded using Zoom software. Only I will have access to the recordings, and they will be stored securely on a computer using password-protected software. The recordings will be deleted once I have completed my analysis.
- When I write up the research, the information will be anonymised (your name will be removed).
- If you would like, I will send you a summary of the research via email when I have completed the project.

What if I require adjustments to be able to participate with the research?
If you would like to take part in the research, I will endeavour to offer flexibility to meet your individual needs and provide reasonable adjustments accordingly (such as to the timing or length of interviews). For example, the interview can be split over two shorter sessions if you require, or the timing can be changed to suit your needs.

Please share any requirements with me when you reach out and if you would like to discuss these further, I will be happy to arrange a preliminary meeting, to which you can choose whether you'd like to bring a trusted adult (such as a family member or carer) to support with decision making about suitable arrangements for you. You will **not** be expected to provide evidence to support such requests.

What are the possible benefits of taking part?
There is very little research looking at experiences of having ME/CFS in secondary school from the perspective of young people themselves. The research will give you the opportunity to share your views, enabling others to learn from your experience with the aim of improving support for children and young people with ME/CFS in the future.

The research will aim to be a positive and informal experience and will give you a chance to reflect on your experience.

What are the possible risks of taking part?
There is a chance that talking about your experiences might feel uncomfortable or remind you of difficult times in your life. The conversation will be led by what you would like to share with me, and you can share as much or as little as you like. Your wellbeing will be prioritised and so we can stop our discussion at any time.

You may also need to take a break or stop the session because of the impacts that it is having on you. You will be able to pause or stop the session at any time.

What will happen to the findings from this research?
The research is for my doctoral studies in Child, Community and Educational Psychology so it will be written up for that. This will be accessible on the internet, and I may also write a shorter version for a professional journal article.

If you would like a summary of findings, please inform me of this via email at the point of consent.

Will my involvement in this research be kept confidential?
Yes, I will follow ethical and legal procedures and ensure that all information you share with me will be kept confidential. I will give you a pseudonym when I save records and write up

the research so no one else will know exactly what you have said. All records will be handled and stored appropriately, and data will be kept in accordance with my University's Data Protection and Handling Policy. The data will be kept for 6 years or more.

Are there times when participant data cannot be kept confidential?
If you share information with me that makes me worried about the safety of you or someone else, I may need to pass information on to others to ensure that you or someone else can be kept safe. I would always try to discuss this with you first if this is the case.

Because I am only meeting with a small number of participants, there is a chance that people who know you very well may recognise some of the things in my research. To protect your identity, I will change your name and I will not mention identifiable information (such as your school or where you live).

Who has given permission for this research?
I am training at the Tavistock and Portman NHS Foundation Trust and they have given permission for this research to take place. The research has received formal approval from the Tavistock and Portman Trust Research Ethics Committee (TREC).

Further information and contact details
For further in information or if you would like to participate, please contact me at ecookson@tavi-port.nhs.uk

My research supervisor, Dr Hannah Lichwa, can be contacted at hlichwa@tavi-port.nhs.uk

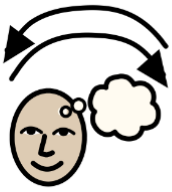
If you have any queries or concerns regarding the conduct of the researcher or any other aspect of this research project, please contact the Head of Academic Registry (academicquality@tavi-port.nhs.uk) or Paru Jeram, Trust Quality Assurance Officer (pjeram@tavi-port.nhs.uk).

Appendix I. Participant Information Sheet (Easy Read)

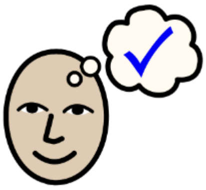
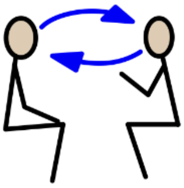
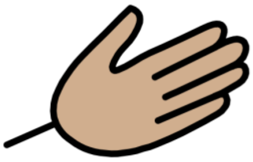
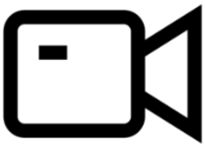
Participant Information Sheet: Easy Read Version

Living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome During Secondary School: a Retrospective Exploration of Experiences of Support

Important things you need to know

	**Who is doing the research?** My name is Ellen Cookson. I am studying to become an Educational Psychologist. I am conducting this piece of research as part of my course.
	**What is the aim of the research?** I would like to explore your experience of living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) during secondary school. I hope to learn how staff can better support young people like yourself.
	**Who can take part in this research?** People who are: • Aged 16 to 25 • Had a diagnosis of ME/CFS during secondary school for at least 3 months
	**Do I have to take part?** You do not have to take part in this study. Your involvement in this study will have no impact on your access to any support that you usually receive.
	**What if I change my mind?** You can change your mind about taking part until 3 weeks after your interview.
	**What will happen to the findings?** When the research is complete, I will write up my findings to share with people who support young people in schools. It is hoped that this will improve support for other people with ME/CFS in the future. I will not include your name in the research.

What is involved in the research?

	You will be asked to give consent. You will need to sign a form and email it to me.
zoom	We will meet on Zoom at a time that suits you (between 8:30am-5pm, Monday-Friday).
	I will tell you more about the research and answer any questions that you might have.
	I will ask you some questions about having ME/CFS during secondary school and there may be a brief writing or drawing activity.
	If you need help to take part, I will try to make changes to meet your needs. For example, the interview can be split over two shorter sessions, or the timing can be changed.
	The meeting will be audio and video recorded using Zoom software.
	If you would like to pause or stop the interview at any point, you will be free to do so. You do not have to give a reason for this.

	The meeting will last about 1 hour. We can split this over two shorter sessions if you would prefer.
	If you like, I will send you a summary of the research via email when I have completed the project. Please let me know at the point of consent if you would like me to do so.

Confidentiality and permissions

	Your data will be stored securely on a password-protected computer and recordings will be deleted after the project is complete.
	The information that you share will be kept confidential. However, if you say anything to me that makes me worried about the safety of you or someone else, I may need to tell someone else. I would try to discuss this with you first if this happens.
	When the research is complete, I will write up my findings to share with people who support young people in schools. I will not include your name in the research.
	I have been given permission for this research from the Tavistock and Portman Trust Research Ethics Committee (TREC).

Further information and contact details

If you would like to take part or have any questions, please get in touch: ecookson@tavi-port.nhs.uk

My research supervisor, Dr Hannah Lichwa, can be contacted at: hlichwa@tavi-port.nhs.uk

If you have any further queries or concerns, please contact the Head of Academic Registry (academicquality@tavi-port.nhs.uk) or the Trust Quality Assurance Officer (pjeram@tavi-port.nhs.uk).

Appendix J. Consent Form

Participant Consent Form

Research Title: Living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome During Secondary School: a Retrospective Exploration of Experiences of Support

Please initial the statements below if you agree with them:

Initial here

1. I have read and understood the information sheet and have had the chance to ask questions.
2. I understand that my participation in this research is voluntary, and I am free to withdraw (stop taking part) at any time until 3 weeks after my interview, without giving a reason.
3. I agree to meet the researcher on Zoom and for my interviews to be recorded.
4. I understand that the information I provide will be confidential and my name will be anonymised (changed) to protect my identity, although there is a chance that people who know me very well may recognise some of the things in the research.
5. I understand that my interview will only be used for this research and will not be shared with anyone else unless the researcher is concerned about the safety of myself and/or someone else.
6. I understand that the findings of this research will be published as a thesis and available for the public to read.
7. I agree to take part in this research.

Name: ………………………………………………………… **Date:** ………………….

Signature: ……………………………………………………………………………......

Email: ………………………………………………………………………………………

Researcher name: Ellen Cookson **Researcher Signature:** …………………….

Thank you for your help!

Appendix K. Interview Schedule

Interview Schedule

Warm-up:
Introductions, check in, rapport

(START RECORDING)

Introduction:

Welcome and thank you

Purpose of the research: The aim of this study is to explore your experience of living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) during secondary school and learn how educational professionals can support and enhance the educational experience and well-being of young people like yourself.

What led to it: Recognition that there is limited research exploring educational experiences of CYP with ME/CFS from the perspective of those with lived experience and so wanting to shine a light on and learn from participants' stories.

Note on terminology: Acknowledge lack of consensus about terminology, regarding whether it should be Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS) or ME/CFS. Ask participants their preferred terminology?

Process: The session is being video recorded so that I can listen to and transcribe the discussion later without missing anything. It will be as anonymous as possible and I will change any identifying features (such as names of people, schools). You are free to stop at any time during the interview.

Have you read and understood the participant information sheet and signed the consent form?: Check for any questions or clarification as necessary.

Confirm participants meet criteria for inclusion (aged 16-25, diagnosis of ME/CFS during secondary school for 3 months, able to communicate verbally in English)

Do you require any reasonable adjustments to facilitate your engagement in this discussion that I am not already aware of?

(If trusted adult present: confirm that they should refrain from sharing their own views or perspectives and should be reminded of confidentiality regarding not sharing information discussed during the interview with anyone else**).**

Are you ready to begin? (Check they have a printed or hand-drawn copy of the GEM grid ready)

Grid Elaboration Method (GEM):

I am interested in what you associate with experiences of secondary school whilst living with ME/CFS. Sometimes a simple drawing or word can be a really helpful way of portraying your thoughts and feelings.

Using the grid in front of you, please draw and/or write one image, word, or phrase in each box that you associate with your experience of having ME/CFS in secondary school.

(Write instructions into meeting chat)

Figure 1. *GEM Grid*

1	2
3	4

(Once complete, participants will be asked to either photograph their completed grid and email it to the researcher or hold it to the webcam to be screenshotted by the researcher.)

Please could you tell me about more about what you've put in each box, and why you think that came to mind/you chose to write/draw this?

Prompts: Why did you choose to write/draw that? Can you tell me a bit more about that? What was that like for you? Can you give me an example?

(OPTIONAL BREAK)

Further Questioning:

- What challenges or difficulties did you face as a result of living with ME/CFS during secondary school?
  Prompts: experiences of learning, peer and teacher interactions

- Can you tell me about your experiences of any support that you did or did not receive at secondary school?

  Can you tell me about a time when you felt well supported in secondary school?
    - *Could you say a little about what, in particular, was helpful about the support offered?*

  Can you tell me about a time when you did not feel well supported in secondary school?
    - *Could you say a little about what, in particular, was not helpful about the support offered?*

(OPTIONAL BREAK)

- Are there any aspects of your identity that you feel may have influenced your experience of living with ME/CFS during secondary school?
  You may consider factors such as race, religion, culture, gender, sexual orientation, or class.

- What would you like educational professions (e.g. teachers, school support staff, psychologists in school) to know or understand about what it’s like to live with ME/CFS in secondary school?

- If I can ask you to use your imagination for a moment. If you were an educational professional supporting a secondary school pupil with ME/CFS, like you were, what support would you put in place for them?

Conclusion:

Ending: Thank you for sharing your experiences. Is there anything else you would like me to know?

(STOP RECORDING)

Debrief: How did you find sharing your experiences with me? Is there any further support that you feel you require following this conversation? Signpost to support listed on the debrief form.

Do you have any questions about the research?

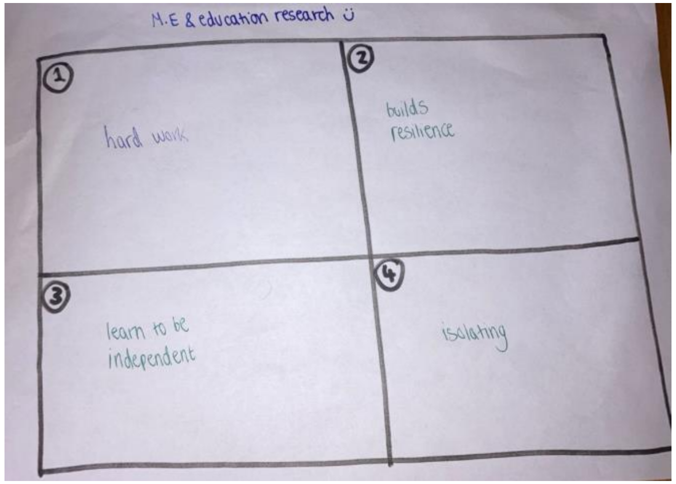
Reminder regarding confidentiality and anonymity in reporting, and option to withdraw until 3 weeks from now.

Check how participants would like to be identified within the research (gender, age, ethnicity, preferred pseudonym)

Are you interested in the opportunity to see a summary of research findings?

Appendix L. Participant GEM Grids

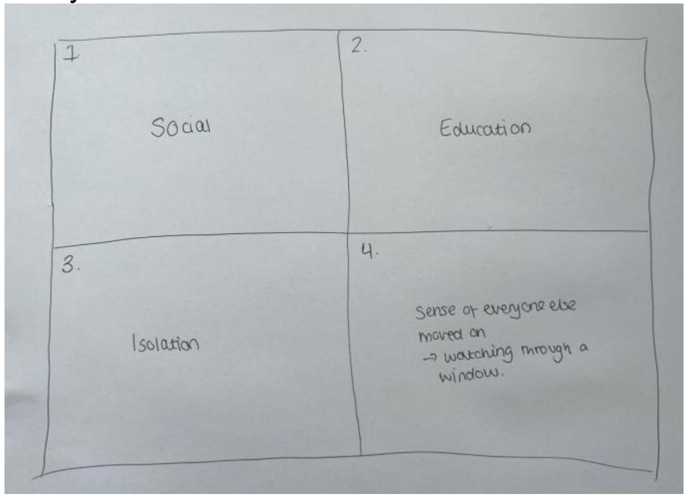
Kiara:



M.E & education research ü

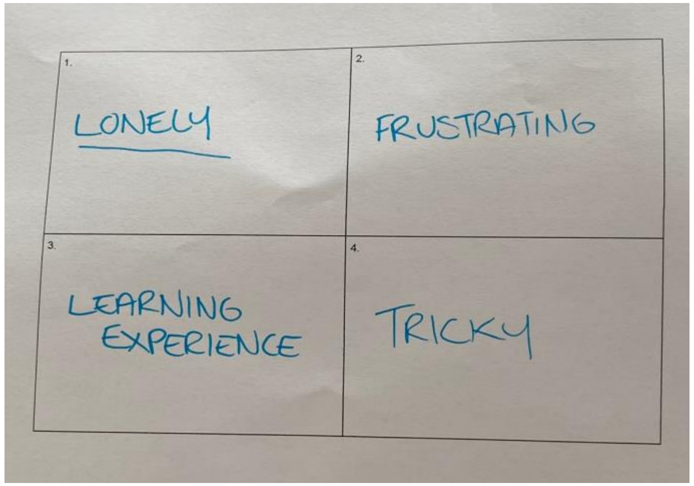
① hard work	② builds resilience
③ learn to be independent	④ isolating

Jenny:



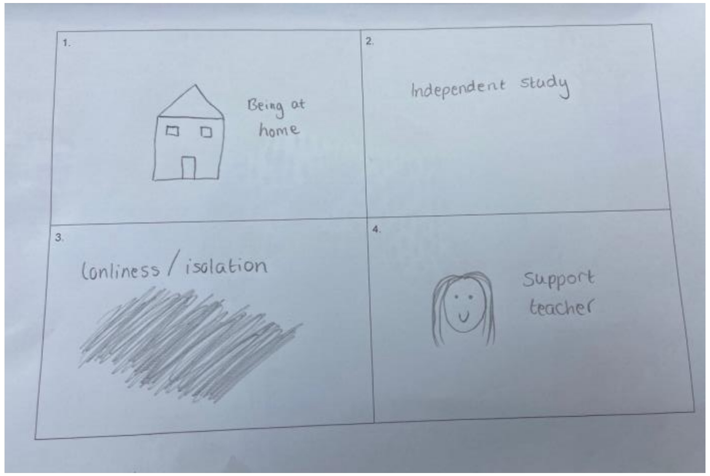
1 Social	2. Education
3. Isolation	4. Sense of everyone else moved on → watching through a window.

Florence:



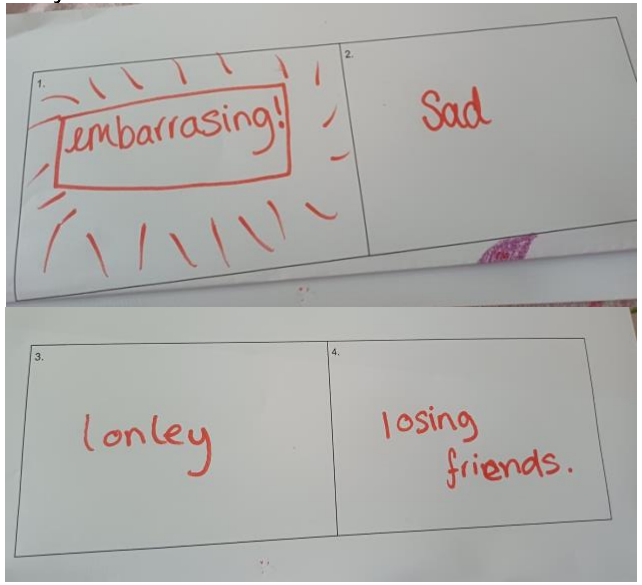
1. LONELY	2. FRUSTRATING
3. LEARNING EXPERIENCE	4. TRICKY

Freya:



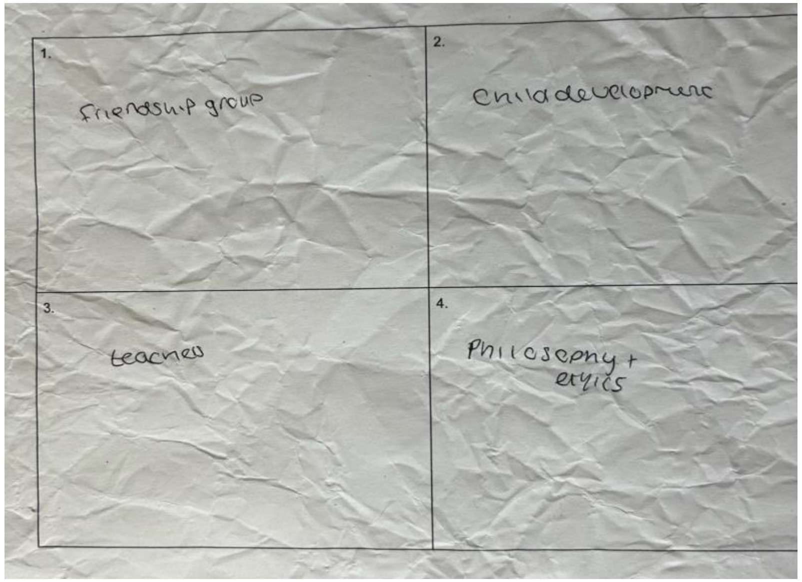
1. Being at home	2. Independent study
3. Lonliness / isolation	4. Support teacher

Lucy:



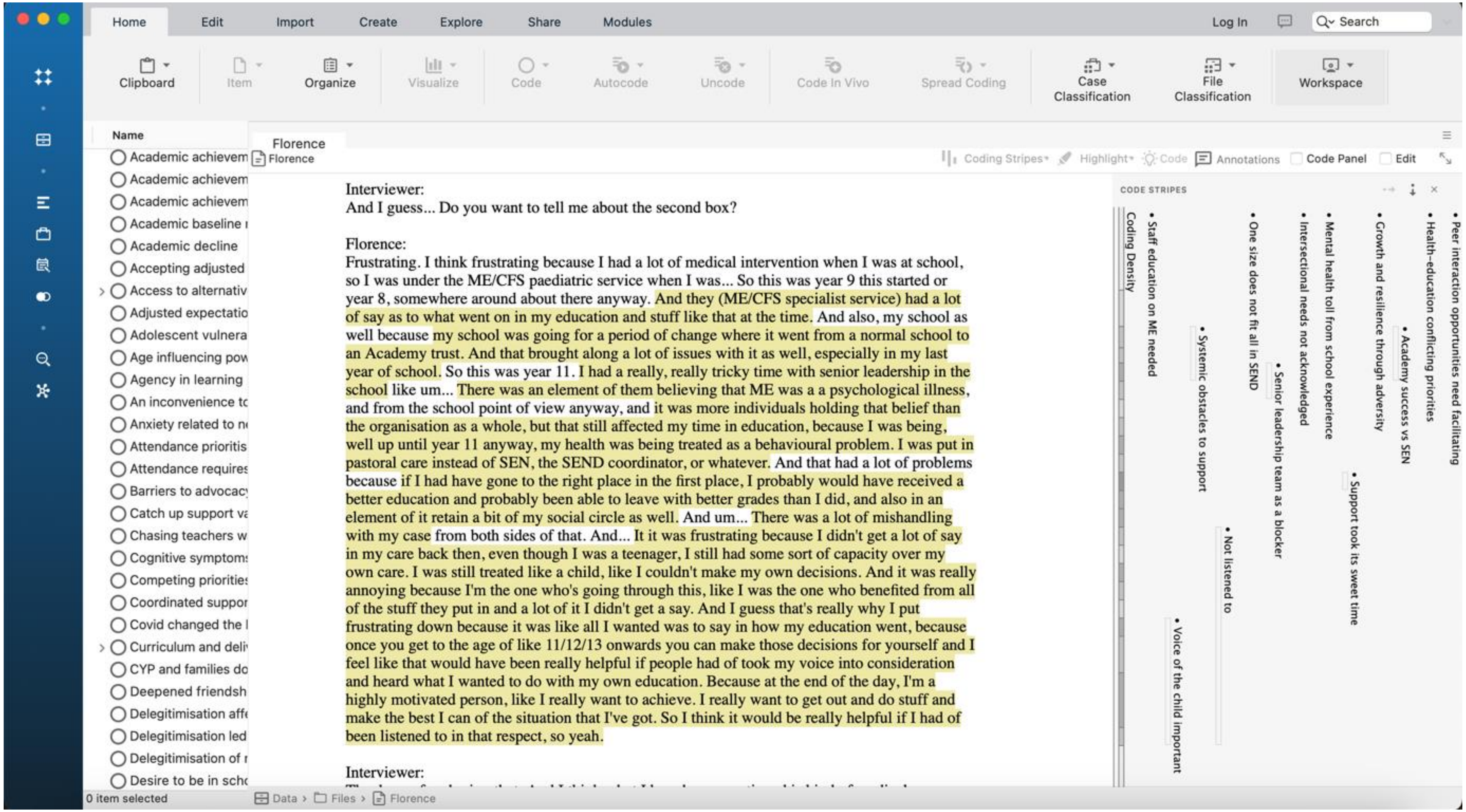
1. embarrasing!
2. Sad
3. lonley
4. losing friends.

Meredith:



1. friendship group
2. child development
3. teachers
4. Philosophy + ethics

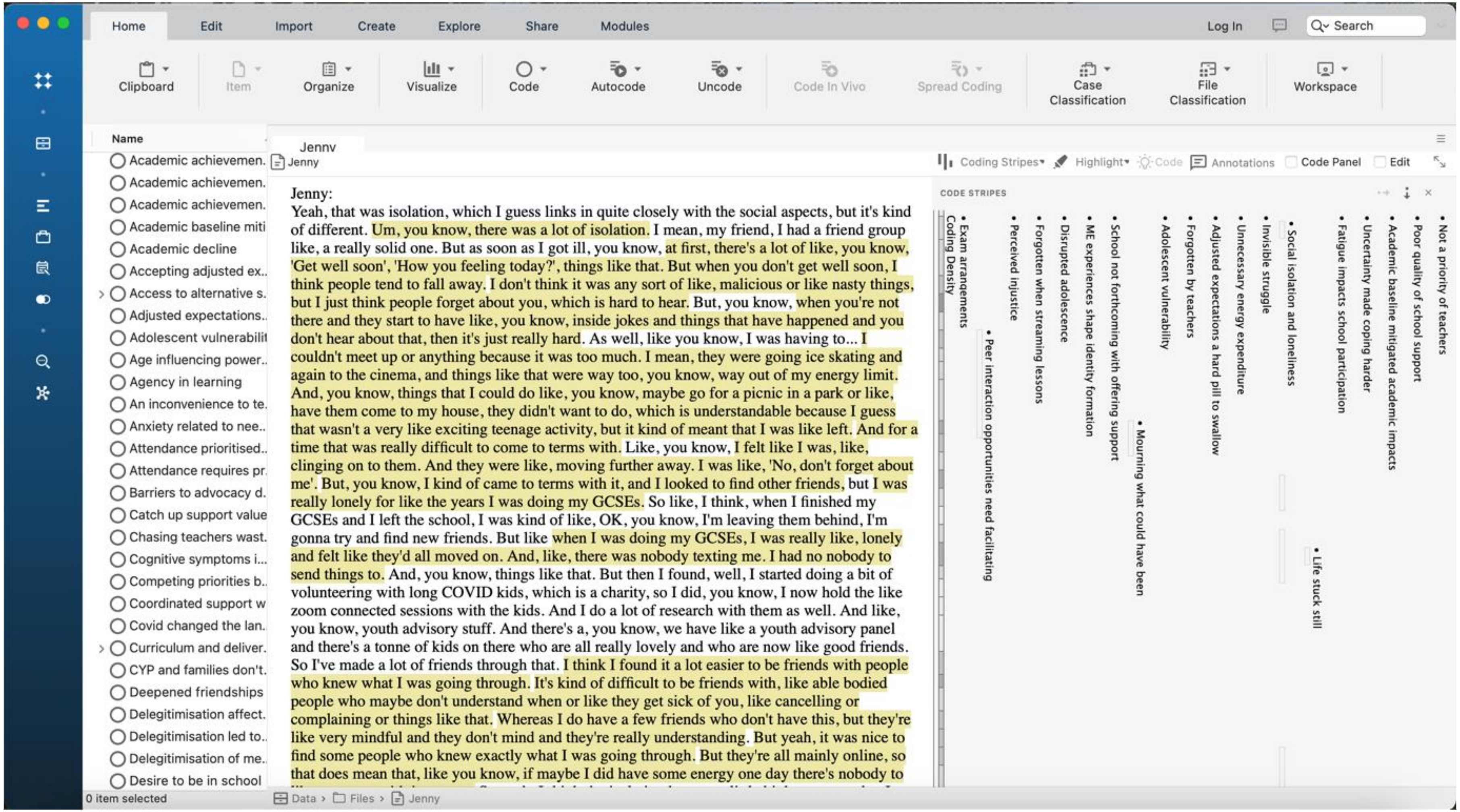
Appendix M. Example Coded Transcript Excerpt



Interviewer:
And I guess... Do you want to tell me about the second box?

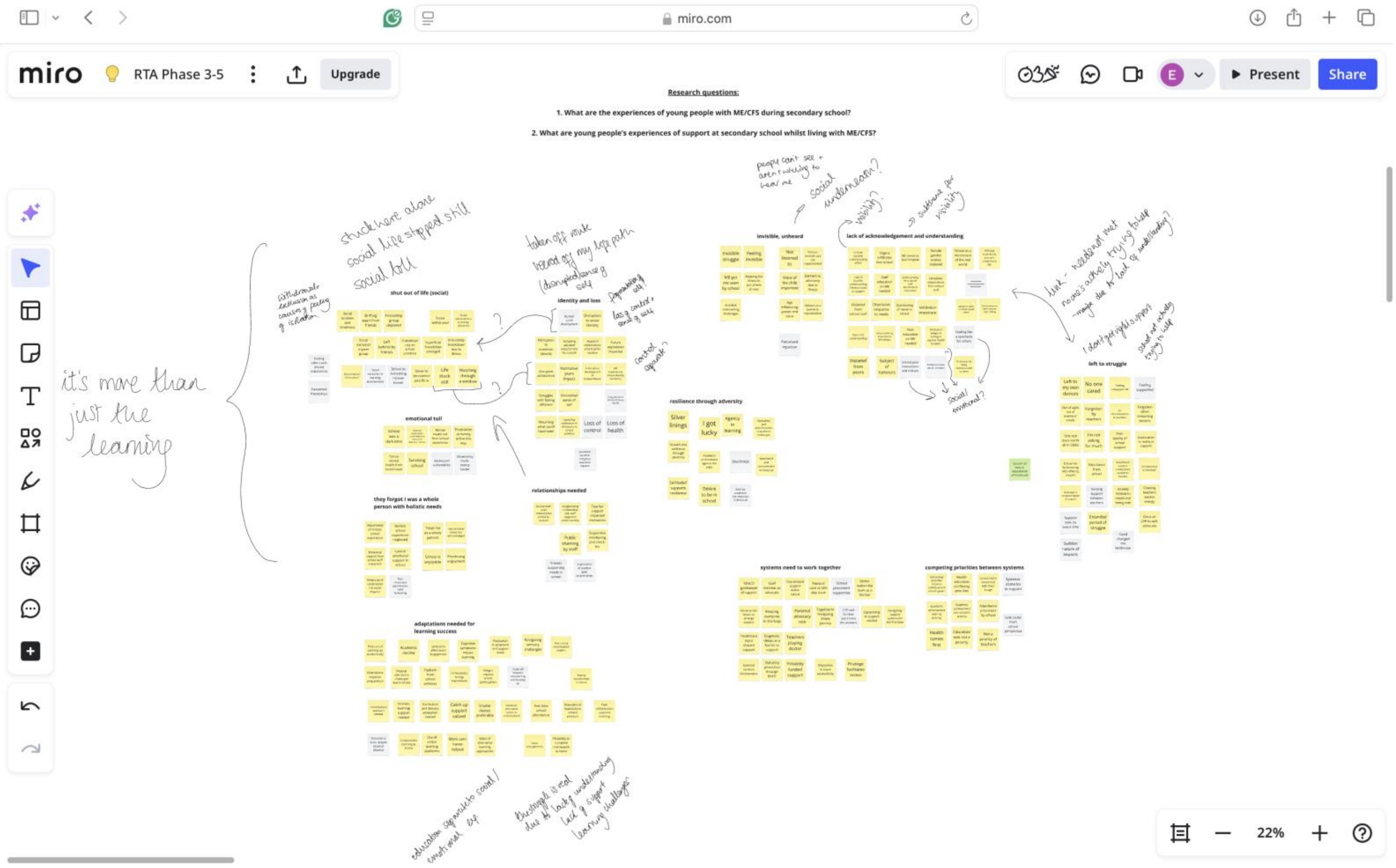
Florence:
Frustrating. I think frustrating because I had a lot of medical intervention when I was at school, so I was under the ME/CFS paediatric service when I was... So this was year 9 this started or year 8, somewhere around about there anyway. And they (ME/CFS specialist service) had a lot of say as to what went on in my education and stuff like that at the time. And also, my school as well because my school was going for a period of change where it went from a normal school to an Academy trust. And that brought along a lot of issues with it as well, especially in my last year of school. So this was year 11. I had a really, really tricky time with senior leadership in the school like um... There was an element of them believing that ME was a a psychological illness, and from the school point of view anyway, and it was more individuals holding that belief than the organisation as a whole, but that still affected my time in education, because I was being, well up until year 11 anyway, my health was being treated as a behavioural problem. I was put in pastoral care instead of SEN, the SEND coordinator, or whatever. And that had a lot of problems because if I had have gone to the right place in the first place, I probably would have received a better education and probably been able to leave with better grades than I did, and also in an element of it retain a bit of my social circle as well. And um... There was a lot of mishandling with my case from both sides of that. And... It it was frustrating because I didn't get a lot of say in my care back then, even though I was a teenager, I still had some sort of capacity over my own care. I was still treated like a child, like I couldn't make my own decisions. And it was really annoying because I'm the one who's going through this, like I was the one who benefited from all of the stuff they put in and a lot of it I didn't get a say. And I guess that's really why I put frustrating down because it was like all I wanted was to say in how my education went, because once you get to the age of like 11/12/13 onwards you can make those decisions for yourself and I feel like that would have been really helpful if people had of took my voice into consideration and heard what I wanted to do with my own education. Because at the end of the day, I'm a highly motivated person, like I really want to achieve. I really want to get out and do stuff and make the best I can of the situation that I've got. So I think it would be really helpful if I had of been listened to in that respect, so yeah.

Interviewer:



Jenny:
Yeah, that was isolation, which I guess links in quite closely with the social aspects, but it's kind of different. Um, you know, there was a lot of isolation. I mean, my friend, I had a friend group like, a really solid one. But as soon as I got ill, you know, at first, there's a lot of like, you know, 'Get well soon', 'How you feeling today?', things like that. But when you don't get well soon, I think people tend to fall away. I don't think it was any sort of like, malicious or like nasty things, but I just think people forget about you, which is hard to hear. But, you know, when you're not there and they start to have like, you know, inside jokes and things that have happened and you don't hear about that, then it's just really hard. As well, like you know, I was having to... I couldn't meet up or anything because it was too much. I mean, they were going ice skating and again to the cinema, and things like that were way too, you know, way out of my energy limit. And, you know, things that I could do like, you know, maybe go for a picnic in a park or like, have them come to my house, they didn't want to do, which is understandable because I guess that wasn't a very like exciting teenage activity, but it kind of meant that I was like left. And for a time that was really difficult to come to terms with. Like, you know, I felt like I was, like, clinging on to them. And they were like, moving further away. I was like, 'No, don't forget about me'. But, you know, I kind of came to terms with it, and I looked to find other friends, but I was really lonely for like the years I was doing my GCSEs. So like, I think, when I finished my GCSEs and I left the school, I was kind of like, OK, you know, I'm leaving them behind, I'm gonna try and find new friends. But like when I was doing my GCSEs, I was really like, lonely and felt like they'd all moved on. And, like, there was nobody texting me. I had no nobody to send things to. And, you know, things like that. But then I found, well, I started doing a bit of volunteering with long COVID kids, which is a charity, so I did, you know, I now hold the like zoom connected sessions with the kids. And I do a lot of research with them as well. And like, you know, youth advisory stuff. And there's a, you know, we have like a youth advisory panel and there's a tonne of kids on there who are all really lovely and who are now like good friends. So I've made a lot of friends through that. I think I found it a lot easier to be friends with people who knew what I was going through. It's kind of difficult to be friends with, like able bodied people who maybe don't understand when or like they get sick of you, like cancelling or complaining or things like that. Whereas I do have a few friends who don't have this, but they're like very mindful and they don't mind and they're really understanding. But yeah, it was nice to find some people who knew exactly what I was going through. But they're all mainly online, so that does mean that, like you know, if maybe I did have some energy one day there's nobody to

Appendix N. Initial Mapping of Patterns Across the Data

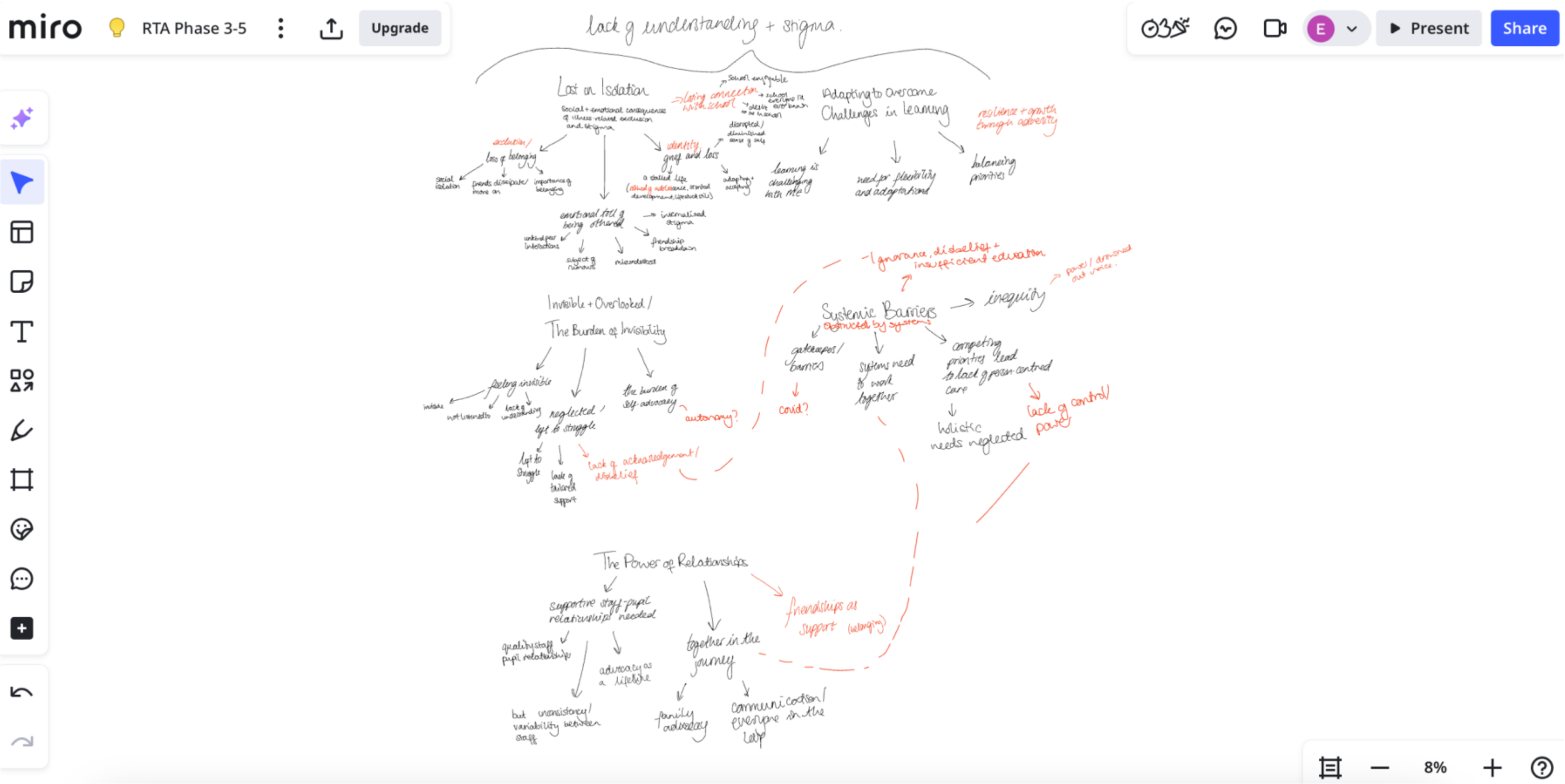


Research questions:

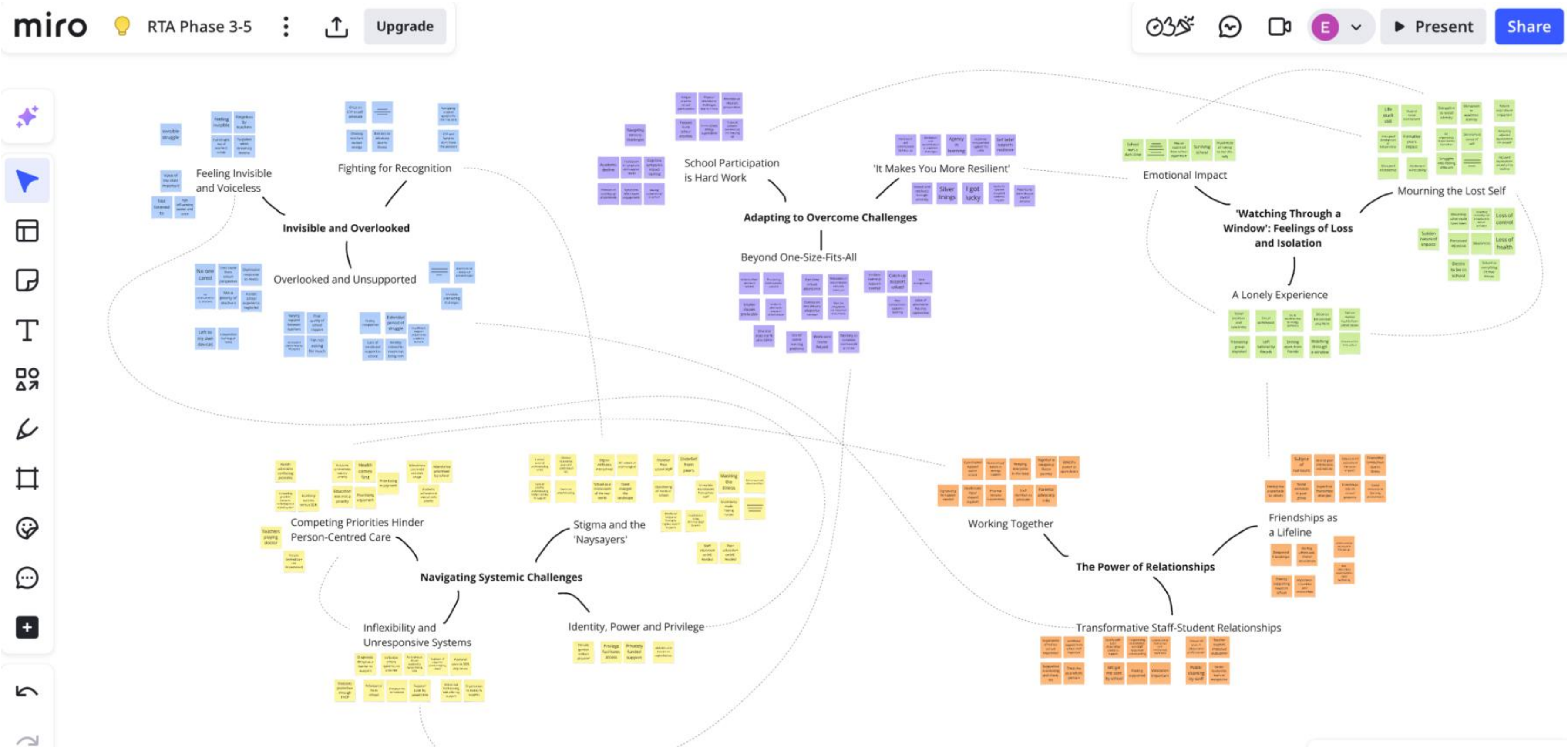
1. What are the experiences of young people with ME/CFS during secondary school?

2. What are young people's experiences of support at secondary school whilst living with ME/CFS?

Appendix O. Refined Thematic Map



Appendix P. Final Thematic Map



Appendix Q. Trusted Adult Consent Form

Trusted Adult Consent Form

Research Title: Living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome During Secondary School: a Retrospective Exploration of Experiences of Support

Please initial the statements below if you agree with them:

Initial here

1. I have read and understood the information sheet and have had the chance to ask questions.
2. I agree to meet the researcher on Zoom and for my involvement in the interview to be recorded.
3. I understand that the information shared within the interview must remain confidential and cannot be shared outside this space, unless I have any safeguarding concerns.
4. I agree to refrain from sharing any of my own views, experiences or perspectives within the interview. I recognise that my role is to support the interviewee to be able to share their own experiences and perspectives.
5. I understand that the findings of this research will be published as a thesis and available for the public to read.
6. I agree to take part in this research as a trusted adult to support the interviewee.

Name: ……………………………………………………… **Date:** ………………….

Signature: ………………………………………………………………………….......

Email: ………………………………………………………………………………………

Researcher name: Ellen Cookson **Researcher Signature:** ……………………

Thank you for your help!

Appendix R. Debrief Form

Participant Debrief Form

Research Title: Living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome During Secondary School: a Retrospective Exploration of Experiences of Support

Thank you for taking part in this research. Following involvement in the research, if have any concerns regarding your physical or mental health, please speak to your GP or healthcare provider.

If you found the process of talking about your experiences distressing and these feelings persist after the research has finished you can:

- Call **Samaritans** (https://www.samaritans.org/how-we-can-help/contact-samaritan/) on 116 123 to access their 24/7 helpline.
- Text SHOUT to **Shout's** (https://giveusashout.org/get-help/) textline on 85258.
- Access information about NHS mental health services at https://www.nhs.uk/nhs-services/mental-health-services/.

Further support and advice specifically related to ME/CFS can be sought from the following charitable organisations:

- **Action for ME** (https://www.actionforme.org.uk) is the UK's leading charity dedicated to improving the lives of people with M.E. They provide information and support to people affected by M.E of all ages. Their helpline (0117 927 9551) is open between 9am-5pm Monday to Friday.
- **The ME Association** provides support, research, advice and a helpline for the community of people affected by ME/CFS. Their helpline (0344 576 5326) is open 365 days a year between 10am-12noon, 2-4pm, and 7-9pm. Alternatively, it can be accessed via email and social media messaging.
- **The Young ME Sufferers Trust** (https://www.tymestrust.org) is the only national ME charity dedicated to children and young people with ME and their families.

You are welcome to contact me by email to discuss any part of your involvement in the research project. If you would like to withdraw your data from the research project, you can request to do so via email up until 3 weeks from now.

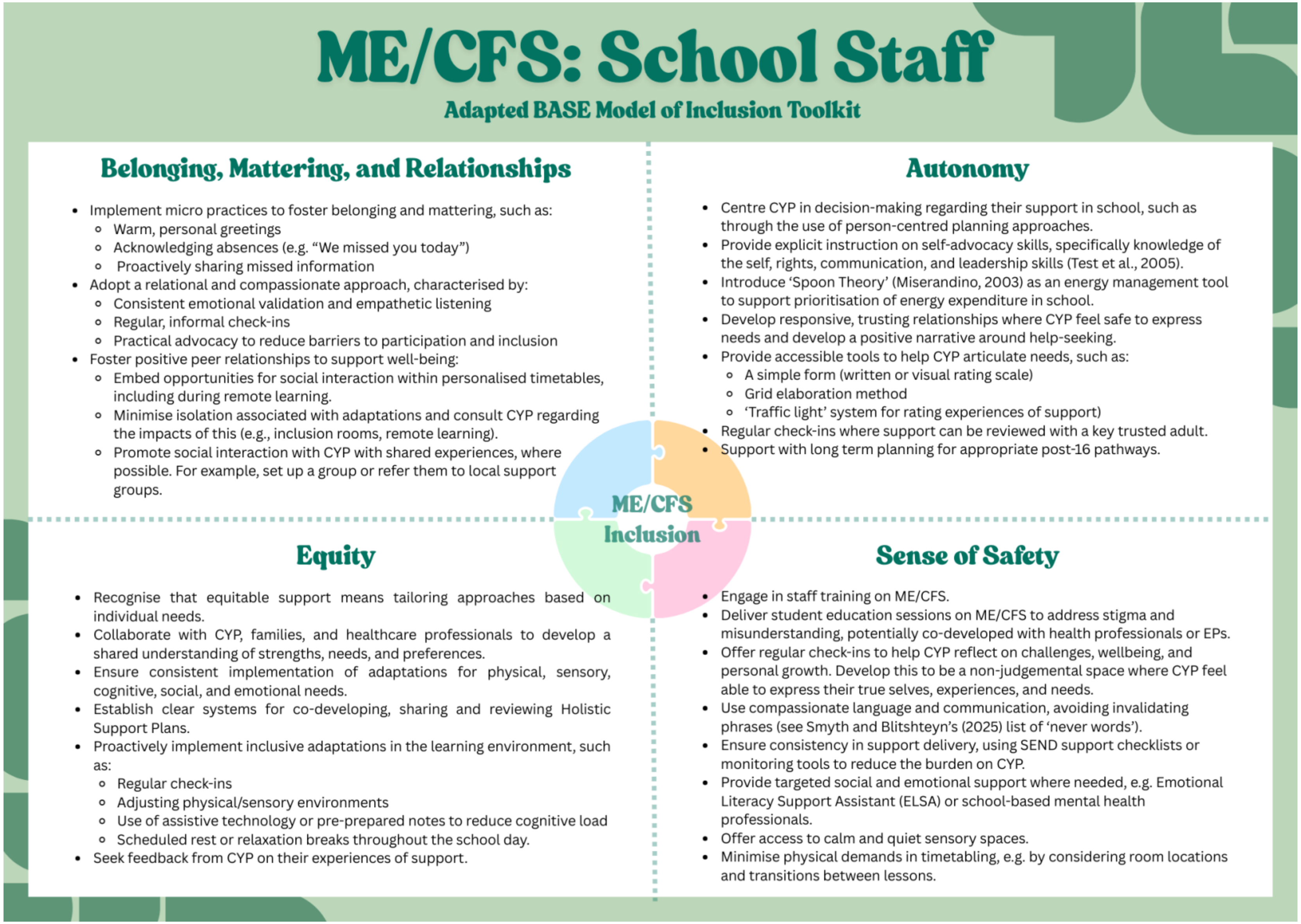
I will now transcribe our conversation and start my analysis. Once this is complete, I will email you to provide the opportunity for you to give feedback on the extent to which my analysis reflects your narrative.

Thank you once again for taking part in this research.

Best wishes,

Ellen Cookson
Trainee Educational Psychologist
Tavistock and Portman NHS Foundation Trust
Email: ecookson@tavi-port.nhs.uk

Appendix S. BASE Toolkit



ME/CFS: School Staff

Adapted BASE Model of Inclusion Toolkit

Belonging, Mattering, and Relationships

- Implement micro practices to foster belonging and mattering, such as:
    - Warm, personal greetings
    - Acknowledging absences (e.g. "We missed you today")
    - Proactively sharing missed information
- Adopt a relational and compassionate approach, characterised by:
    - Consistent emotional validation and empathetic listening
    - Regular, informal check-ins
    - Practical advocacy to reduce barriers to participation and inclusion
- Foster positive peer relationships to support well-being:
    - Embed opportunities for social interaction within personalised timetables, including during remote learning.
    - Minimise isolation associated with adaptations and consult CYP regarding the impacts of this (e.g., inclusion rooms, remote learning).
    - Promote social interaction with CYP with shared experiences, where possible. For example, set up a group or refer them to local support groups.

Autonomy

- Centre CYP in decision-making regarding their support in school, such as through the use of person-centred planning approaches.
- Provide explicit instruction on self-advocacy skills, specifically knowledge of the self, rights, communication, and leadership skills (Test et al., 2005).
- Introduce 'Spoon Theory' (Miserandino, 2003) as an energy management tool to support prioritisation of energy expenditure in school.
- Develop responsive, trusting relationships where CYP feel safe to express needs and develop a positive narrative around help-seeking.
- Provide accessible tools to help CYP articulate needs, such as:
    - A simple form (written or visual rating scale)
    - Grid elaboration method
    - 'Traffic light' system for rating experiences of support)
- Regular check-ins where support can be reviewed with a key trusted adult.
- Support with long term planning for appropriate post-16 pathways.

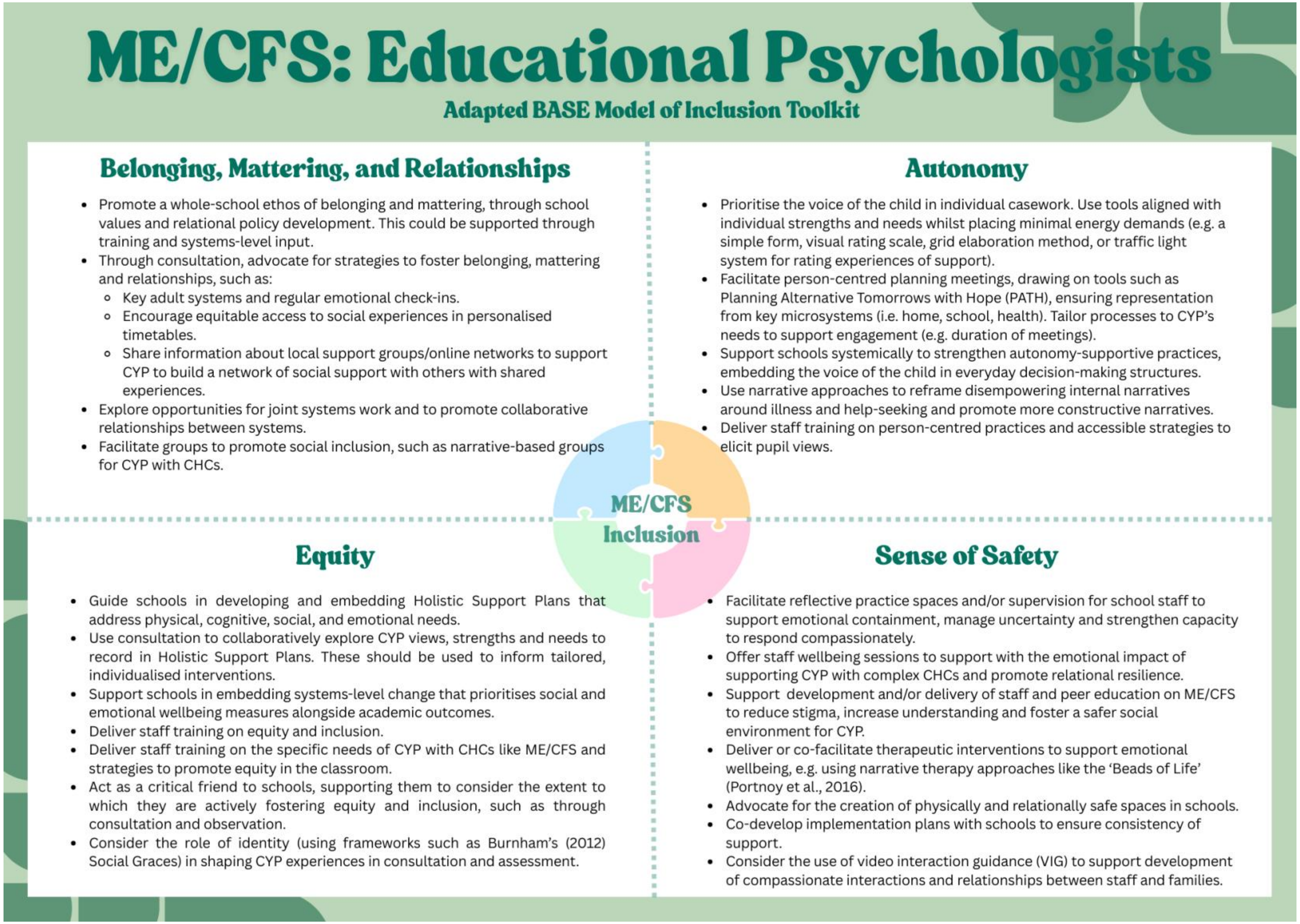
ME/CFS
Inclusion

Equity

- Recognise that equitable support means tailoring approaches based on individual needs.
- Collaborate with CYP, families, and healthcare professionals to develop a shared understanding of strengths, needs, and preferences.
- Ensure consistent implementation of adaptations for physical, sensory, cognitive, social, and emotional needs.
- Establish clear systems for co-developing, sharing and reviewing Holistic Support Plans.
- Proactively implement inclusive adaptations in the learning environment, such as:
    - Regular check-ins
    - Adjusting physical/sensory environments
    - Use of assistive technology or pre-prepared notes to reduce cognitive load
    - Scheduled rest or relaxation breaks throughout the school day.
- Seek feedback from CYP on their experiences of support.

Sense of Safety

- Engage in staff training on ME/CFS.
- Deliver student education sessions on ME/CFS to address stigma and misunderstanding, potentially co-developed with health professionals or EPs.
- Offer regular check-ins to help CYP reflect on challenges, wellbeing, and personal growth. Develop this to be a non-judgemental space where CYP feel able to express their true selves, experiences, and needs.
- Use compassionate language and communication, avoiding invalidating phrases (see Smyth and Blitshteyn's (2025) list of 'never words').
- Ensure consistency in support delivery, using SEND support checklists or monitoring tools to reduce the burden on CYP.
- Provide targeted social and emotional support where needed, e.g. Emotional Literacy Support Assistant (ELSA) or school-based mental health professionals.
- Offer access to calm and quiet sensory spaces.
- Minimise physical demands in timetabling, e.g. by considering room locations and transitions between lessons.



ME/CFS: Educational Psychologists

Adapted BASE Model of Inclusion Toolkit

Belonging, Mattering, and Relationships

- Promote a whole-school ethos of belonging and mattering, through school values and relational policy development. This could be supported through training and systems-level input.
- Through consultation, advocate for strategies to foster belonging, mattering and relationships, such as:
  - Key adult systems and regular emotional check-ins.
  - Encourage equitable access to social experiences in personalised timetables.
  - Share information about local support groups/online networks to support CYP to build a network of social support with others with shared experiences.
- Explore opportunities for joint systems work and to promote collaborative relationships between systems.
- Facilitate groups to promote social inclusion, such as narrative-based groups for CYP with CHCs.

Autonomy

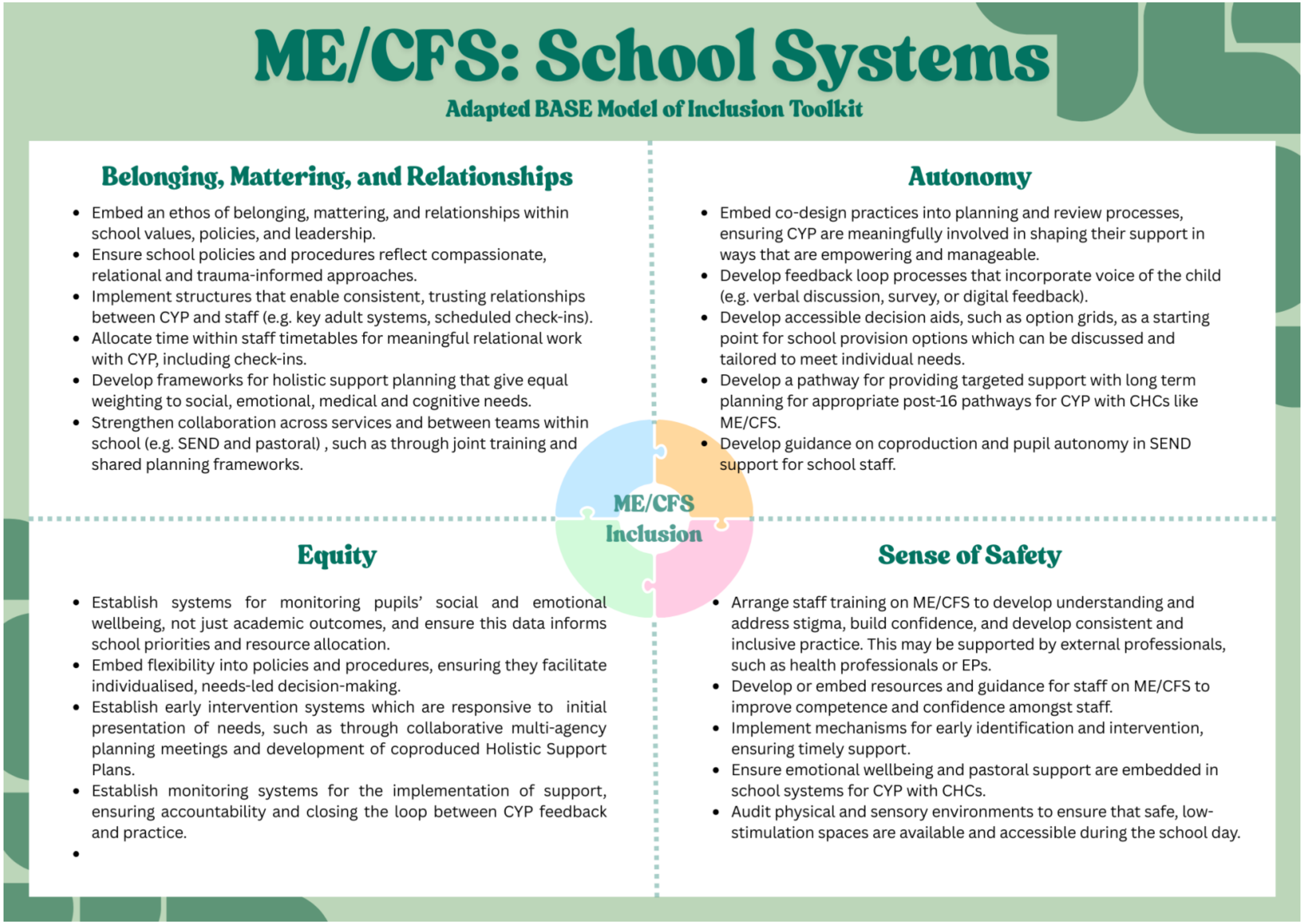
- Prioritise the voice of the child in individual casework. Use tools aligned with individual strengths and needs whilst placing minimal energy demands (e.g. a simple form, visual rating scale, grid elaboration method, or traffic light system for rating experiences of support).
- Facilitate person-centred planning meetings, drawing on tools such as Planning Alternative Tomorrows with Hope (PATH), ensuring representation from key microsystems (i.e. home, school, health). Tailor processes to CYP's needs to support engagement (e.g. duration of meetings).
- Support schools systemically to strengthen autonomy-supportive practices, embedding the voice of the child in everyday decision-making structures.
- Use narrative approaches to reframe disempowering internal narratives around illness and help-seeking and promote more constructive narratives.
- Deliver staff training on person-centred practices and accessible strategies to elicit pupil views.

Equity

- Guide schools in developing and embedding Holistic Support Plans that address physical, cognitive, social, and emotional needs.
- Use consultation to collaboratively explore CYP views, strengths and needs to record in Holistic Support Plans. These should be used to inform tailored, individualised interventions.
- Support schools in embedding systems-level change that prioritises social and emotional wellbeing measures alongside academic outcomes.
- Deliver staff training on equity and inclusion.
- Deliver staff training on the specific needs of CYP with CHCs like ME/CFS and strategies to promote equity in the classroom.
- Act as a critical friend to schools, supporting them to consider the extent to which they are actively fostering equity and inclusion, such as through consultation and observation.
- Consider the role of identity (using frameworks such as Burnham's (2012) Social Graces) in shaping CYP experiences in consultation and assessment.

Sense of Safety

- Facilitate reflective practice spaces and/or supervision for school staff to support emotional containment, manage uncertainty and strengthen capacity to respond compassionately.
- Offer staff wellbeing sessions to support with the emotional impact of supporting CYP with complex CHCs and promote relational resilience.
- Support development and/or delivery of staff and peer education on ME/CFS to reduce stigma, increase understanding and foster a safer social environment for CYP.
- Deliver or co-facilitate therapeutic interventions to support emotional wellbeing, e.g. using narrative therapy approaches like the 'Beads of Life' (Portnoy et al., 2016).
- Advocate for the creation of physically and relationally safe spaces in schools.
- Co-develop implementation plans with schools to ensure consistency of support.
- Consider the use of video interaction guidance (VIG) to support development of compassionate interactions and relationships between staff and families.



ME/CFS: School Systems

Adapted BASE Model of Inclusion Toolkit

Belonging, Mattering, and Relationships

- Embed an ethos of belonging, mattering, and relationships within school values, policies, and leadership.
- Ensure school policies and procedures reflect compassionate, relational and trauma-informed approaches.
- Implement structures that enable consistent, trusting relationships between CYP and staff (e.g. key adult systems, scheduled check-ins).
- Allocate time within staff timetables for meaningful relational work with CYP, including check-ins.
- Develop frameworks for holistic support planning that give equal weighting to social, emotional, medical and cognitive needs.
- Strengthen collaboration across services and between teams within school (e.g. SEND and pastoral) , such as through joint training and shared planning frameworks.

Autonomy

- Embed co-design practices into planning and review processes, ensuring CYP are meaningfully involved in shaping their support in ways that are empowering and manageable.
- Develop feedback loop processes that incorporate voice of the child (e.g. verbal discussion, survey, or digital feedback).
- Develop accessible decision aids, such as option grids, as a starting point for school provision options which can be discussed and tailored to meet individual needs.
- Develop a pathway for providing targeted support with long term planning for appropriate post-16 pathways for CYP with CHCs like ME/CFS.
- Develop guidance on coproduction and pupil autonomy in SEND support for school staff.

ME/CFS Inclusion

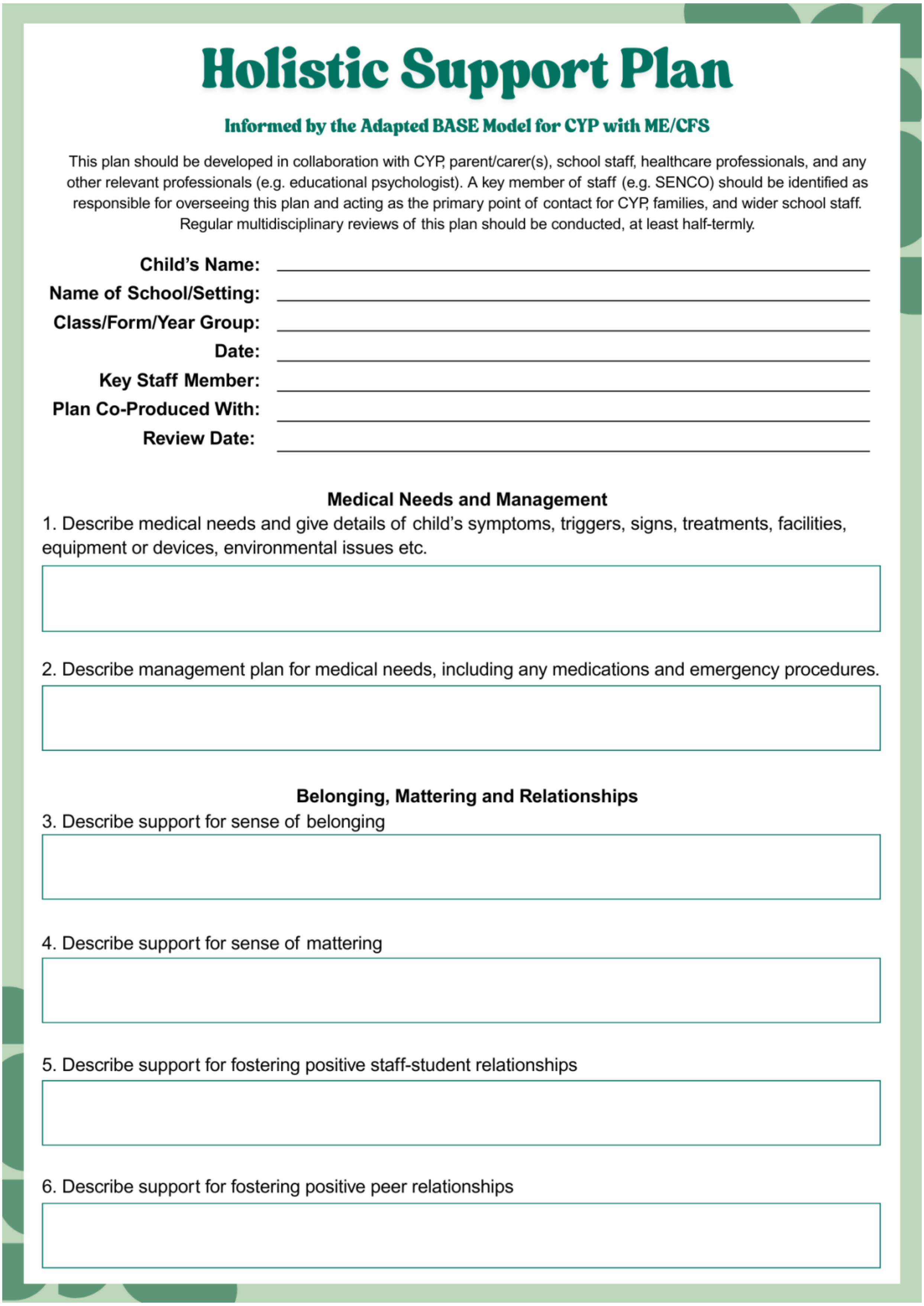
Equity

- Establish systems for monitoring pupils' social and emotional wellbeing, not just academic outcomes, and ensure this data informs school priorities and resource allocation.
- Embed flexibility into policies and procedures, ensuring they facilitate individualised, needs-led decision-making.
- Establish early intervention systems which are responsive to initial presentation of needs, such as through collaborative multi-agency planning meetings and development of coproduced Holistic Support Plans.
- Establish monitoring systems for the implementation of support, ensuring accountability and closing the loop between CYP feedback and practice.
-

Sense of Safety

- Arrange staff training on ME/CFS to develop understanding and address stigma, build confidence, and develop consistent and inclusive practice. This may be supported by external professionals, such as health professionals or EPs.
- Develop or embed resources and guidance for staff on ME/CFS to improve competence and confidence amongst staff.
- Implement mechanisms for early identification and intervention, ensuring timely support.
- Ensure emotional wellbeing and pastoral support are embedded in school systems for CYP with CHCs.
- Audit physical and sensory environments to ensure that safe, low-stimulation spaces are available and accessible during the school day.

Appendix T. Holistic Support Plan Template



Holistic Support Plan

Informed by the Adapted BASE Model for CYP with ME/CFS

This plan should be developed in collaboration with CYP, parent/carer(s), school staff, healthcare professionals, and any other relevant professionals (e.g. educational psychologist). A key member of staff (e.g. SENCO) should be identified as responsible for overseeing this plan and acting as the primary point of contact for CYP, families, and wider school staff. Regular multidisciplinary reviews of this plan should be conducted, at least half-termly.

Child's Name: ______________________________
Name of School/Setting: ______________________________
Class/Form/Year Group: ______________________________
Date: ______________________________
Key Staff Member: ______________________________
Plan Co-Produced With: ______________________________
Review Date: ______________________________

Medical Needs and Management

1. Describe medical needs and give details of child's symptoms, triggers, signs, treatments, facilities, equipment or devices, environmental issues etc.

2. Describe management plan for medical needs, including any medications and emergency procedures.

Belonging, Mattering and Relationships

3. Describe support for sense of belonging

4. Describe support for sense of mattering

5. Describe support for fostering positive staff-student relationships

6. Describe support for fostering positive peer relationships

Autonomy

7. Describe support for self-advocacy (e.g. self-advocacy skill intervention, introduction to ‘Spoon Theory’, option grids for support)

8. Describe approaches to support the elicitation of student views and feedback

Sense of Safety

9. Describe adaptations required within the school environment (e.g. access to quiet space, sensory environment)

10. Describe approach to combatting stigma amongst staff and students (e.g. staff training, peer education)

11. Identify key trusted adult(s) in school

12. Describe support for social and emotional needs (e.g. daily check-ins, ELSA, narrative approaches)

Equity

13. Describe cognition and learning adaptations required to support equitable access to learning

14. Additional vulnerabilities to be aware of when promoting equity and inclusion?

Additional Comments