The Lived Experiences of Siblings of Children With Complex Medical Needs: An Interpretative Phenomenological Analysis

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Abstract

Children with complex medical needs (CMN) denotes the most medically fragile children and young people with the greatest intensive health care needs. Following advances in healthcare, child mortality has been in decline since the 1980s leading to an increase in the number of children with life-limiting and life-threatening conditions. Their siblings experience certain challenges as a result of having a brother or sister with CMN. While some voluntary organizations offer support, there is a current lack of understanding and guidance as to how schools and Educational Psychologists can help meet their needs.

The current study sought to explore the experiences of siblings using interpretative phenomenological analysis to understand the impact of having a sibling with CMN on family and school life. A sample of 6 well siblings aged 11 to 15 years old participated in individual online semi-structured interviews. Five master themes were identified from the data: ‘My Family Life’, ‘My Growth and Development’, ‘The Importance of Relationships at School’, ‘Aspects of School That Help and Hinder’ and ‘Time for Change’.

The findings broadly reflected existing research: well siblings undertook caring responsibilities associated with their brother or sister with CMN; they had close, loving relationships with their family; they experienced disrupted sleep and worried about their sibling when they were ill; and they felt that friends and teachers did not understand their challenges. Novel findings included that carers in the home could provide respite to the whole family, school rules and policies could both help and hinder their school experience, and diversity and inclusion were important aspects of well siblings’ ideal school.

The findings were contextualized using Bronfenbrenner’s ecological systems theory as a framework, with links to attachment theory and post-traumatic growth. Implications for schools included recommendations around homework deadlines, consequences for being late and providing sibling support groups; it was recommended that Educational Psychologists work systemically with schools to support teachers’ understanding of the needs of siblings of children with CMN, to gain the views of well siblings and to signpost schools and families to further sources of support.

Keywords: siblings, complex medical needs, family life, school, ecological systems

Declaration

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I declare that while registered as a degree student at UEL, I have not been a registered or enrolled student for another award of this university or of any other academic or professional institution.

I declare that no material contained within this has been used in any other submission for an academic award.

I declare that my research required ethical approval from the University Ethics Committee (SREC) and that confirmation of approval is embedded within this thesis.

DRWoolfson

Deborah Rose Woolfson
April 2024

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List of Abbreviations Used

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CMN	Complex Medical Needs
DSM-5	Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition
EP	Educational Psychologist
IPA	Interpretative Phenomenological Analysis
MMAT	Mixed Methods Appraisal Tool
PTSD	Post-Traumatic Stress Disorder
RQ	Research Question
SEND	Special Educational Needs and Disabilities
SENCo	Special Educational Needs Co-ordinator
TEP	Trainee Educational Psychologist
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Dedication

In loving memory of Keith and Jasmine.

Chapter 1: Introduction

1.1 Chapter outline

This research aims to explore the lived experiences of siblings of children and young people[1] with complex medical needs (CMN), with a particular focus on their experiences of family life and school. The research employs interpretative phenomenological analysis (IPA) to investigate how schools and Educational Psychologists (EPs) can best support the siblings of children with CMN.

In this introductory chapter, the key terms used in the study are defined; relevant national and international context is set out; the theories underpinning the research are delineated; my own personal and professional experiences of sibling relationships and CMN are outlined; and the rationale for the current study, the research aims and the questions it seeks to answer are established.

1.2 Definition of key terms.

1.2.1 Siblings

For the purposes of this research, the term *siblings* is used to refer to children who share one or more parents. They may be siblings by birth, adoption, fostering or special guardianship order, half-siblings, or step-siblings.

The current study is concerned with siblings of children with CMN. Eligibility for participation in the study is limited to siblings who ordinarily reside at the same address as their brother or sister with CMN most of the time, as it is deemed that those who live apart will have

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[1] For brevity's sake, children and young people will be referred to as 'children' hereafter throughout this research.

markedly different day-to-day experiences from those who live together. The terms *well sibling(s)* and *siblings(s) of children with CMN* are used interchangeably throughout the research.

1.2.2 Complex medical needs

This second key term, used in the current research, encounters less consensus in its definition. Children with CMN are those deemed to be the most medically fragile with the greatest intensive health care needs (E. Cohen et al., 2011). They form a subsection of those commonly referred to as *children with special health care needs* (E. Cohen et al., 2018). They include children with “a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, or patients with cancer/cancer survivors with ongoing disability in multiple areas” (E. Cohen et al., 2011, p. 529).

According to the Royal College of Paediatrics and Child Health (RCPCH) having CMN results from one or more underlying health conditions (RCPCH, 2018). This may include those born extremely prematurely, those with inherited conditions or chronic illness, and those who may have sustained a life changing injury (RCPCH, 2018, p. 1). Children with CMN may have one or more life-limiting or life-threatening conditions. Life-limiting conditions describe diseases with no reasonable hope of cure and that will ultimately be fatal whereas life-threatening conditions are those for which curative treatment may be available (Larcher et al., 2015).

Children with CMN are commonly described in research as having “chronic conditions associated with medical fragility, substantial functional limitations, increased health and other service needs, and increased health care costs” (E. Cohen et al., 2018, p. 203). This latter definition is adopted by the current study.

Terms such as *complex health needs* and *medical complexity* are synonymous with *CMN* (Gallo et al., 2021). Recruitment of participants for the current study was initially undertaken via The Maypole Project, a charity which uses the term *complex medical needs* to refer to the children (and their families) that it supports. Therefore, *complex medical needs*, or rather its abbreviation, *CMN*, is employed throughout the current study to maintain consistency and avoid confusion or any unintended distress among participants and their families that could occur if an ill child's sibling or parent encountered a term with which they were unfamiliar.

1.3 Context and background

The following section explores the current socio-political landscape in which the research is situated at an international and national level.

1.3.1 International context

A number of international treaties and organisations exist which outline how countries are expected to respect the rights of disabled children, including those with CMN.

1.3.1.1 United Nations Convention on the Rights of the Child. The United Nations Convention on the Rights of the Child (UNCRC) outlines the rights that all children up to the age of 18 should have (*Convention on the Rights of the Child*, 1989). Apart from the USA, every member of the United Nations has ratified the UNCRC. By signing up to it, countries have made a legally-binding agreement to ensure its implementation (*UN Convention On The Rights Of The Child*, n.d.).

Certain parts of the UNCRC are particularly relevant to children with CMN and their siblings, including Article 2 (non-discrimination), Article 3 (best interests of the child), Article 6 (life, survival and development), and Article 28 (right to education). By signing up to the UNCRC, governments across the globe have committed to ensuring that all children, including those with CMN and their siblings, are treated fairly, are enabled to develop to their full potential and have access to education (*Convention on the Rights of the Child*, 1989). Furthermore, they have publicly committed to ensuring that decisions will be made in the best interests of children and that discipline in schools will respect their dignity and rights (*Convention on the Rights of the Child*, 1989).

1.3.1.2 United Nations Convention on the Rights of Persons with Disabilities. Also of relevance to children with CMN is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), adopted in 2006 and ratified by 186 member states (*Convention on the Rights of People with Disabilities*, 2006). Article 1 of the UNCRPD sets out its intention to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (*Convention on the Rights of People with Disabilities*, 2006, art. 1). It defines persons with disabilities as those with long-term physical, mental, intellectual or sensory impairments.

Article 7 of the Convention focuses specifically on disabled children, outlining their right to have freedoms and express their views on an equal basis with their non-disabled peers (*Convention on the Rights of People with Disabilities*, 2006, art. 7). By ratifying the UNCRPD, member states agree to protect and promote the human rights of disabled people as set out in the Convention and its implementation is subject to scrutiny by the United Nations (*UN Convention on the Rights of Persons with Disabilities*, 2006).

1.3.1.3 Support organisations for siblings. At an international level, there are several organisations providing support to the siblings of children with CMN. The Sibling Support Project is one of the largest of these, serving families across the United States (Nguyen, 2023). The charity supports the siblings of children with developmental, health and mental health conditions through *Sibshops*, which aim to help develop networks of siblings who can provide peer support to one another, and to increase understanding among parents and professionals as to how siblings may be affected by having a brother or sister with complex needs (Nguyen, 2023).

Similarly, in Australia, an organisation called Siblings Australia provides support to siblings of children with disabilities, helping them to connect with one another and educating parents and professionals about the struggles they may face (*Siblings Australia*, 2023).

The existence of charities like these around the world suggests the need for such services and a gap in the provision of them by governments at a national level and by councils at a local level.

1.3.2 National context.

1.3.2.1 Improvements in healthcare. Improvements in healthcare generally, and in antenatal and neonatal care more specifically, are believed to have driven the decline in child mortality since 1980 (E. Cohen et al., 2018). In England and Wales, there were 2,226 deaths of infants under one year in 2020 (Office for National Statistics, 2022) compared with 3,078 deaths for the same age group in 2010 (Office for National Statistics, 2013). Congenital malformations, deformations and chromosomal abnormalities were the main causes of death of children under 16 in England and Wales in 2020 (Office for National Statistics, 2022).

The result of such improvements is that babies born prematurely, with low birth weight or various congenital abnormalities, survive for longer (E. Cohen et al., 2011). As child mortality decreases, the number of children living with chronic life-threatening illnesses increases (Ho et al., 2019). These children may require the involvement of a range of agencies, technology, medical professionals and support systems (Chrvala & Sharfstein, 1999). It was calculated that 86,625 children and young people aged 0 to 19 years were living with a life-limiting or life-threatening condition in England in 2017/18 (Fraser et al., 2021). Alongside each of these children is a family living with illness and uncertainty every day.

1.3.2.2 Statutory duties of schools. In the UK, children with CMN are protected in law by the Equality Act 2010 and the Children and Families Act 2014. The Equality Act 2010 replaced and consolidated decades of earlier laws which sought to eliminate discrimination based on a range of protected characteristics, including age, race and disability. Nurseries, schools, colleges and universities, like all organisations providing a public service, have to abide by the Act, ensuring their practices do not directly or indirectly discriminate, harass or victimise those considered to be disabled (Government Equalities Office, 2010).

Additionally, part 3 of the Children and Families Act 2014, which underpins the Special Educational Needs and Disabilities (SEND) Code of Practice (Department for Education & Department of Health, 2015), outlines the statutory duties of organisations, including schools, that work with, and support, children with SEND in England. Furthermore, statutory guidance issued under section 100 of the Children and Families Act 2014 ensures that governing bodies are held accountable for ensuring that “arrangements are in place in school to support pupils with medical conditions”, and that “the needs of children with medical conditions are properly understood and effectively supported” (Department for Education, 2015, p. 4).

1.3.2.3 Role of the voluntary sector. Organisations in the voluntary sector are primarily aimed at creating positive social change as opposed to profit (Reach Volunteering, 2017). In the United Kingdom, latest data shows that there are around 250,000 Voluntary, Community and Social Enterprises (Department for Culture, Media & Sport, 2022). Almost half of these have an income of less than £10,000, and many rely on volunteers to achieve their goals (Reach Volunteering, 2017). Up to 5% of the UK’s Voluntary Community and Social Eneterprises engage in government contracts every year, with 68% of these coming from local government (Department for Culture, Media & Sport, 2022). At present, the support received by siblings of children with CMN appears to be provided primarily by charitable organisations.

1.3.2.4 Charities supporting siblings. In England, several charities have the express aim of providing support to the families of children with CMN, or to the wider group of families of children with disabilities, which encompasses those with CMN. These include Sibs, Together for Short Lives and The Maypole Project.

***1.3.2.4.1 Sibs*.** Sibs provides support to those who grow up with a brother or sister with SEND or a serious long-term health condition. It represents over half a million young siblings and over 1.7 million adult siblings (Sibs, n.d.-a). The charity aims to enhance the lives of siblings through information and support initiatives, and by advocating for service provision throughout the country. One of its current areas of work is to enhance the identification and support of siblings in schools (Sibs, n.d.-b). As well as providing support to well siblings, its website provides advice and resources for schools to better support well siblings in order that they may thrive in the classroom and beyond (‘Recommendations for Schools’, n.d.).

1.3.2.4.2 Together for Short Lives. Together for Short Lives is a charity which supports families caring for a seriously ill child. It provides a helpline and information that is easily digestible to allow families to navigate the system so that they can make the most of their time together (Together for Short Lives, n.d.-b). The charity campaigns for better policies to help families access the right care and support, and fundraises for children’s hospices (Together for Short Lives, n.d.-b). Together for Short Lives also works in partnership with a number of organisations, including the Council for Disabled Children, an umbrella charity which brings together professionals, practitioners and policy-makers, and the Disabled Children’s Alliance, a coalition of over 50 organisations campaigning for better health and social care for disabled children and their families (Together for Short Lives, n.d.-a).

1.3.2.4.3 The Maypole Project**.** The Maypole Project is a charity based in southeast England which provides a range of therapies and activities for children with CMN and disabilities (The Maypole Project, n.d.). It also aims to educate carers and professionals in the areas of loss and bereavement, as well as supporting and preserving their mental and physical wellbeing (The Maypole Project, n.d.). Crucially, the Maypole Project strives to support families of children with CMN when and for as long as necessary. This can include before, during and after diagnosis, and in some cases, involvement with families continues after a bereavement (The Maypole Project, n.d.).

1.3.3 Theoretical context

Several psychological theories are deemed relevant to the experiences of siblings of children with CMN. Firstly, Bronfenbrenner's (1979) Ecological Systems Theory provides a framework for the current study, locating development in the context of multiple, interacting systems which affect, and are affected by, the child at the core.

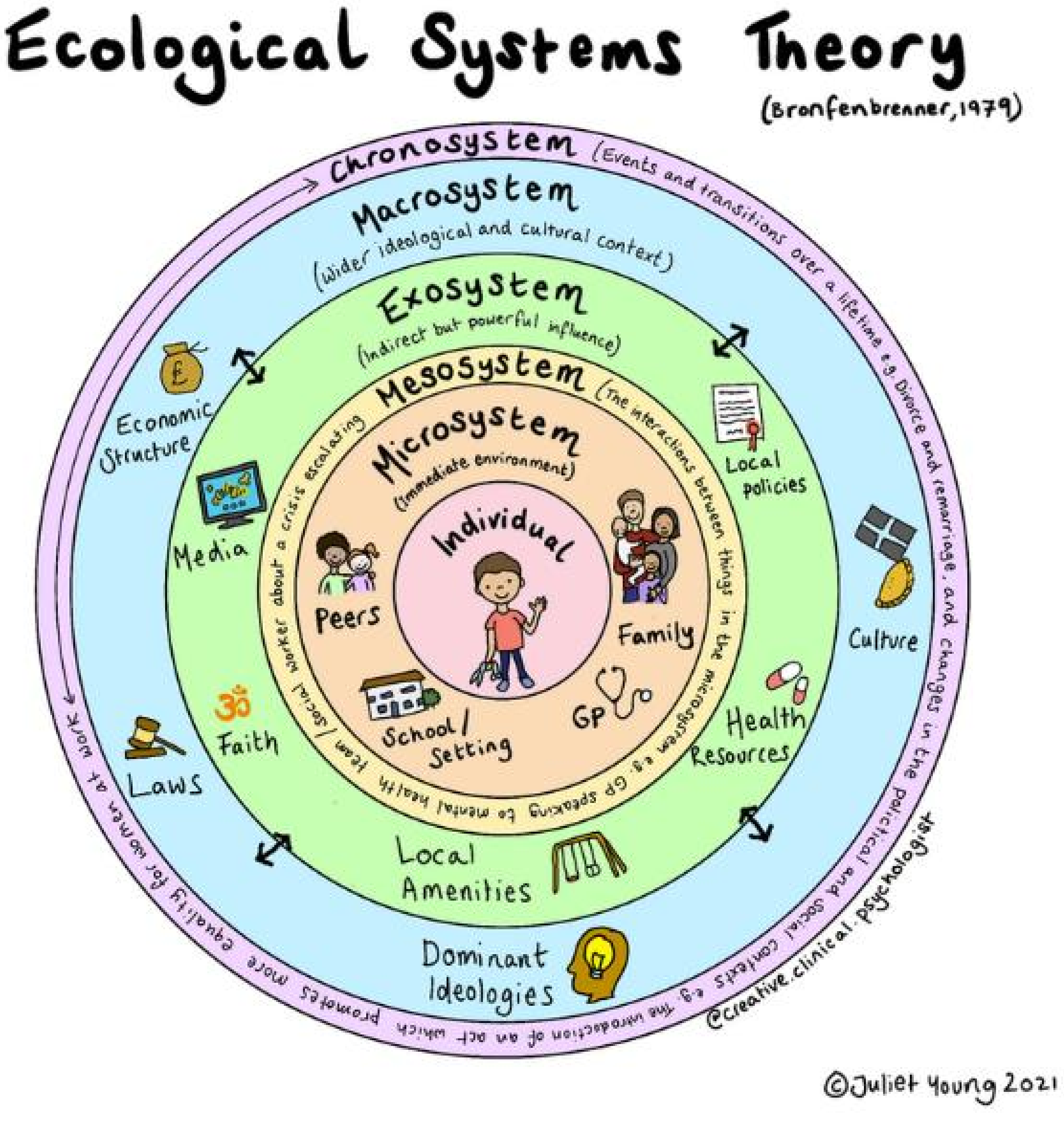
Additionally, the current study postulates that having a sibling with CMN has a profound psychological impact on well siblings, which could be experienced as traumatic. A sense of belonging at school may act as a protective factor. Therefore, theories of school belonging, sibling relationships, and child trauma are all deemed to be relevant to the current study.

1.3.3.1 Ecological systems theory. Bronfenbrenner's (1979) Ecological Systems Theory provides a useful framework for the current research. It posits that a child's development is intertwined with the different environments in which the child exists and the relationship between those environments, including those with which they may never directly interact (Bronfenbrenner, 1979).

Taking Ecological Systems Theory as a framework to explore the lived experiences of siblings of children with CMN, the study considered their development within, and the interactions between, the microsystem (their family; their school), the mesosystem (the communication between family and school), the exosystem (the parents' economic situation which determines where the child lives and the school they attend), the macrosystem (the country in which they live, its laws and culture) and the chronosystem (the period of time since their sibling's diagnosis) (see Figure 1.1).

Figure 1.1

Depiction of Bronfenbrenner's (1979) Ecological Systems Theory (Young, 2021)



Furthermore, Bronfenbrenner sets out that "what matters for behavior and development is the environment as it is perceived, rather than as it may exist in 'objective' reality" (1979, p. 4). This perspective underpins the current study's methodological foundations as the research seeks to comprehend how siblings of children with CMN experience family life and school from their perspective.

1.3.3.2 Psychological impact and childhood trauma. Research has shown that having a sibling with CMN can have a profound psychological impact. For example, siblings of children with disabilities, such as cystic fibrosis, cerebral palsy and myelodysplasia (blood cancer), scored significantly higher than a control group on subscales measuring problems with cognitive functioning, delinquency and fighting (Breslau et al., 1981). Furthermore, in order to normalize the experience of having an ill child in the family, parents may treat all children in the family in a similar manner, resulting in the healthy siblings potentially believing they too are ill (Fanos, 2014). Children aged 2 to 8 who experience the death of a sibling are at greater risk of presenting symptoms of distress such as sleep, appetite, bowel and bladder disturbances, or withdrawn and irritable behaviour (Crehan, 2004). Older children, aged 8 to 12, develop a realisation of their own mortality, leading to a tendency toward fearfulness, phobias and hypochondria (Crehan, 2004). Living with a child with CMN may also result in anticipatory grief (Najafi et al., 2022).

A traumatic event is defined as a frightening, dangerous, violent event which may be experienced first-hand or witnessed (*What Is Child Trauma?*, 2015). This can include, but is not limited to, abuse, neglect, natural disasters, war, serious accidents or life-threatening illnesses (Peterson, 2018). Experiencing severe trauma can lead to the development of Post-traumatic stress disorder (PTSD) in around 1 in 3 people (National Health Service, 2021). Nevertheless, it is recognised that the development of PTSD is determined by a subjective, personal response to trauma and is not an inevitability (Salmon & Bryant, 2002). Given the life-limiting or life-threatening nature of the illnesses experienced by many children with CMN, it follows that their siblings could be at risk of experiencing the illness as traumatic, and some may develop PTSD as a result.

1.3.3.3 School belonging. School belonging has been defined as “the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment” (Goodenow, 1993, p. 80). A sense of school belonging has been found to be a protective factor for academic outcomes and to promote positive mental health and wellbeing in siblings of autistic young people (Gregory et al., 2020). One study has found that high levels of school belonging acted, to some extent, as a buffer against fighting and bullying behaviours for students with and without disabilities (Rose et al., 2016). On the contrary, those who do not feel they fit in at school are at risk of engaging in fighting, bullying, vandalism, disruptive behaviour, risk-taking behaviours, disengagement from school and early school drop-out (Allen et al., 2018; Goodenow, 1993). A sense of belonging is believed to be particularly crucial during adolescence (age 12 to 18) when young people are forming their own identities during their transition from childhood to adulthood (Allen et al., 2018). Thus, a sense of school belonging may be particularly important for siblings of children with CMN who face a unique set of challenges in their home lives.

1.3.3.4 Sibling relationships. Sibling relationships have been described as “the most influential and long-lasting of human relationships” (Tabor, 2016, p. 1). Following interviews with approximately 9,000 people, White (2001) concluded that sibling relationships decline steeply in early adulthood in terms of proximity, contact, and giving and receiving help, suggesting that sibling bonds are strongest in childhood.

Research has found that younger siblings are directly affected by the trajectory of their older siblings (Zukow-Goldring, 2002). For example, younger siblings are at an increased risk of drug use if they have an older sibling who engaged in this type of behaviour (Milevsky, 2011). On the plus side, positive relationships between siblings are linked to better cognitive, emotional and social skills throughout childhood and adolescence (Milevsky, 2011). Nevertheless, these findings apply when both siblings are typically developing. Conger et al. (2009) highlight the difficulties with sibling socialisation when one child's development is atypical; in such circumstances, the other, typically developing sibling, tends to assume the role of socialization agent irrespective of birth order or gender composition. It is noteworthy that the typically developing sibling may also benefit by gaining greater tolerance, empathy and maturity relative to their peers (Dykens, 2005). Thus, siblings of children developing atypically can both impart knowledge and skills to, as well as learning them from, their brothers and sisters.

1.4 Researcher's position

Here I outline how various aspects of the current research are relevant to me given my professional and personal experiences of encountering them. First person is used due to the personal nature of the content.

1.4.1 Professional experience of working with children with CMN.

My first experience of working with children with CMN was at the age of 17, when I embarked on a gap year as a volunteer teaching assistant in Chile. One of my pupils, Martina[2],

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[2] All names have been changed to protect identities.

had a percutaneous endoscopic gastrostomy tube, used a wheelchair and had a compacted frame. I later found out that Martina had Osteogenesis Imperfecta – Type III, more commonly known as brittle bone disease, the average life expectancy for which is just 10 years (Paterson et al., 1996). Despite her prognosis, Martina is now in her late 20s and thriving as a television producer and voice actor.

Prior to commencing the Doctorate, as a teacher and special educational needs co-ordinator (SENCo), I took pride in meeting the needs of all children with SEND in and outside of the classroom, but none more so than those with the most severe and complex needs. Working in a mainstream school, one of my most memorable experiences was receiving an apology letter handwritten by a Year 9 pupil, Paul, for arriving late to school. Paul had medulloblastoma, a type of brain tumour, as well as a variety of other diagnoses including epilepsy and attention deficit hyperactivity disorder (ADHD) and had joined the school two years before, unable to read or write.

Another highlight was accompanying Jacob, a Year 7 pupil, on a residential trip, during which he participated in a climbing activity. On the trip, Jacob attempted to ascend a climbing wall, encouraged by his peers. Jacob, who had cerebral palsy, made it all the way to the top of the wall, at which point all his classmates erupted in cheers, celebrating as though his achievement was their own.

As a trainee Educational Psychologist (TEP), one of the most insightful and enjoyable experiences I have had has been working with a specialist setting for two-year olds with complex needs. Working with children with CMN has taught me the transformational impact of high-quality provision, high expectations and inclusivity, and above all, to never underestimate a child's potential.

1.4.2 Professional experience of working with siblings of children with CMN.

In 2018/19, while undertaking a Master's of Psychology at the University of East London (UEL), I saw the position of Activities Volunteer at The Maypole Project advertised on the university's volunteering portal. Hoping to expand my experience of working with children with the highest level of need, I applied for it and soon afterwards, began volunteering at play sessions and helping to run activities for children with CMN and their siblings. I was inspired and humbled by the positivity of the children, their parents, staff and volunteers, and was able to see first-hand the difference the charity made to families of children with CMN. The activities ranged from soft play and bowling to horse-riding and sailing lessons. It was clear that these sessions were held in high regard by families who otherwise may not have been able to provide such experiences for their children given the challenges they faced and the additional support their children needed.

When I applied for the Doctorate in Educational and Child Psychology at UEL, I found myself calling upon my experience of volunteering with The Maypole Project to demonstrate my passion for the field more so than any other position I had previously held. During my first year of the Doctorate, I attended a session run by the Chief Executive Officer of The Maypole Project on supporting families of children with CMN, with a particular focus on grief and loss. It was this session which sparked my interest in conducting my thesis on the lived experiences of siblings of children with CMN. Having gained the experience I needed for the Doctorate by volunteering with The Maypole Project, it seemed fitting that I should undertake my thesis on a topic relevant to the charity and the families it serves.

Although most of my experience of working with well siblings came from volunteering, as a teacher, I taught three sisters, the middle of whom, Jasmine, was diagnosed with Leukaemia when she was in Year 8. I remember vividly the head teacher sharing the news during a staff briefing, and passing on a request from her older sister, Faith, not to ask her about how Jasmine was doing. Initially, I was surprised by this request, and whenever I saw Faith, I had to bite my tongue not to ask about Jasmine, since I instinctively wanted to do so. Nevertheless, I wanted to respect Faith's wishes and acknowledge her as the expert in her own life. It is this sort of information I hope to derive from the current study that may help teachers and EPs to better understand the experiences and wishes of siblings of children with CMN, to help give them the best possible school experience.

1.4.3 Personal Experience of sibling relationships

I am the younger of two sisters, born two years apart. My sister and I are extremely different and yet remarkably similar. As children, the differences were pronounced; I was shy, academic and compliant, whereas my sister was gregarious, artistic and rebellious. Although I am younger, I have tended to take on the advisory role described by Zukow-Goldring (2002) as usually being adopted by the older sibling. According to my sister, this simply means I am *bossy*. Despite having taken quite different paths in life, it is clear we share the same values and moral compass. My sister is and always will be one of the most important people in my life, even if we do not see or speak to each other regularly.

1.4.4 Personal experience of CMN

In November 2015, at the age of 60, my stepdad was diagnosed with motor neurone disease (MND). Over the following two and a half years, his mobility, speech, breathing and quality of life deteriorated. In March 2018, he died due to complications resulting from MND. Before my stepdad's diagnosis, he was a strong, fit and healthy adult. His illness was all the more shocking given the active, adventurous life he had led until its onset.

I struggled to make sense of my stepdad's illness and rapid decline, and still do. It devastated my family and shook the foundations of our world. Yet, my stepdad was an adult who had lived a full and vibrant life. The thought of being a close family member of a child with life-limiting or life-threatening condition is unfathomable. Yet, there are siblings of children with CMN in that position attending school every day.

1.5 Research rationale.

1.5.1 Importance of CMN, sibling relationships and school experience

The diagnosis of a life-threatening or life-limiting illness in childhood is devastating for families. The researcher's own experience, both personal and professional, has made her particularly sensitive to the needs of children with CMN and the effects a diagnosis can have on those closest to them.

The lives of siblings are intertwined. Research findings may help to make predictions about the average sibling relationship, but the reality for siblings of children with CMN is not average. The current study aims to explore the lives of siblings of children with CMN from their own perspective, with a particular focus on time spent with their family and at school, and how the two interact and affect one another.

As a TEP, I have begun to wonder if there was anything else I could have done to support the siblings of children with CMN when I was teaching. It may be that adaptations were made at a whole school level, for example, with regards to attendance, of which I was not aware. As an EP, I want to ensure I am well versed in how EPs and schools can support siblings of children with CMN to give them the best possible school experience, and to be able to share this learning with other professionals in the field.

1.5.2 Gaps in research

As well as developing knowledge and skills which set them apart from their peers, siblings of children with CMN may experience their brother or sister's condition as a traumatic event. At present, there appears to be limited awareness and understanding of the lived experiences of these children. To the researcher's knowledge, there is no guidance for EPs on how to support them.

The siblings of children with CMN each have their own unique story, but these stories are likely to be woven with common threads. It is hoped that the current study will give a platform to the voices of siblings of CMN, helping to raise their profile so that, when a child is born or diagnosed with a chronic condition associated with medical fragility, schools recognize and respond appropriately to the extraordinary circumstances experienced by their siblings.

1.5.3 Potential role for schools and EPs

The current study helps to ensure that the exceptional stories of these siblings are told, heard and acted upon. By employing IPA, the research aims to identify the ways in which schools and EPs can support siblings of children with CMN to thrive at school and beyond. EPs are in a unique position in that they regularly have contact with the children with the highest level of need, as well as their parents or carers, and a number of different professionals working with them. Therefore, they may have access to the systems around the family which can help to effect change on the ground, leading to better care and support for siblings of children with CMN. The researcher's goal is to disseminate these findings through publication of this research.

1.6 Aims of the Current Research

The current research aimed to explore how siblings of children with CMN experience family life and school. To this end, semi-structured interviews were undertaken with participants and transcripts were analysed using IPA, which has been described as being particularly useful for examining topics that are "complex, ambiguous and emotionally laden" (J. A. Smith & Osborn, 2015, p. 41). Arguably, the subject matter of the current research – how the siblings of children with CMN experience family life and school – fits this description to a tee.

It is hoped that the analysis of participants' responses to interviews leads to a clear set of recommendations for schools and EPs to ensure that the siblings of children with CMN receive the support they need and deserve to thrive inside and outside of the classroom.

1.7 Chapter summary

In this chapter, the key terms used in the current study were defined and the national and international legislation and context in which the research is set were presented. The researcher's professional and voluntary work with children with CMN, and her personal experiences of sibling relationships and CMN, which have motivated and inspired her interest in the subject, and which undoubtedly colour her analysis of participants' responses in the current study, were set out. The following chapter presents a review of existing relevant literature.

Chapter 2: Literature Review

2.1 Chapter outline

Having set out the context in which the current study takes place in the previous chapter, this chapter presents the existing research into the lived experiences of siblings of children with CMN. A systematic search and review of the literature is undertaken and the quality of each included article is evaluated using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). A detailed thematic synthesis of the findings from the existing research is presented. Gaps in the literature are identified, paving the way for the current qualitative study into the lived experiences of siblings of children with CMN.

2.2 Literature search

A systematic literature search was carried out to establish the current body of research relevant to the research question: what are the lived experiences of siblings of children with CMN? This section details the search strategy employed to find relevant literature including the databases searched, the key words used, and the inclusion and exclusion criteria applied.

2.2.1 Search strategy

Using the EBSCO Host, the following three databases were searched on 09.02.2023 for relevant studies: APA PsychINFO, CINAHL Complete and Education Research Complete. In consultation with the UEL librarian, these databases were deemed most likely to return results relevant to the subject matter. Snowballing was also employed to find additional research, that is, the reference lists of included articles were searched for further relevant literature. The databases were searched again in March 2024, to identify further relevant literature, once the findings of the current study had been identified. Such research was included in the 'Discussion' chapter of the current study.

2.2.2 Search terms

In order to focus the search on the experiences of siblings of children with complex medical needs, the search terms were categorized into two groups as follows:

i. sibling* OR brother* OR sister*

AND

ii. "complex medical needs" OR "medical complexity" OR "complex needs" OR "complex health needs" OR "life threatening" OR "life-threatening" OR "life limiting" OR "life-limiting"

The databases were searched for articles which included at least one from each group of terms in their title. This search strategy was adopted to help ensure that the results were both broad enough to encompass all relevant research while restrictive enough to ensure that the results would be applicable to the research question.

The search was limited to peer reviewed articles and to research published within the last decade (i.e. 2012 onwards) so that it reflected the times, e.g. the digital age and up-to-date legislation.

2.2.3 Search results

The initial search returned 33 articles across the 3 databases, 14 of which were duplicates. The remaining 19 studies were screened for inclusion in the current literature review. After an initial screening of the title and abstract, 6 studies were excluded as they were deemed not to contribute to answering the research question, leaving 13 studies to undergo a full text screening. Following the full text screening, a further 7 studies were excluded and 6 remained. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) chart shows the number of articles found, retrieved and included in the current study (see Appendix A).

2.2.4 Inclusion and exclusion criteria

The next step involved reading the title and abstract of each article and applying the following inclusion criteria to each study:

i. The study examined the impact of having a brother or sister with CMN on the well sibling.
ii. The study examined the views and perspective of the well sibling, (i.e. not solely conveying the parents' or professionals' views).
iii. The majority of well siblings in the study were children or young people aged 0 to 18 (with some flexibility if the age upper limit of the age range exceeded 18).

Studies were excluded if they focused on:

i. Literature reviews/meta-analyses where some/all of the articles included are beyond the scope of the current review (i.e. earlier than 2012).
ii. The evaluation of a particular intervention or development of a tool.
iii. Siblings of children with SEND more generally, rather than specifically on siblings of children with CMN.
iv. An experience not relevant to the majority of siblings in the UK, e.g. the American model of *medical homes*.

The exclusion criteria helped to ensure that the findings were relevant to the population of siblings of children with CMN in the UK as a whole, and not solely for a specific subgroup, for example, those who had experienced a particular intervention.

2.2.5 Snowballing

The number of relevant articles found was considered to be relatively low and so a snowballing approach was used to identify further literature to be included in the current review. Thus, the reference lists on each of the six included studies were searched using the 'Find' tool on Microsoft Word. A further four studies which had not appeared through the original database search were deemed relevant to the literature review and the decision was taken to include them. Thus, a total of ten studies were subject to critical appraisal.

2.3 Appraising the evidence

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was employed to establish the quality and relevance of the research included in the literature review. The MMAT was chosen as it allows researchers to appraise qualitative, quantitative and mixed methods studies using a single tool, in contrast to tools such as the Weight of Evidence metric developed by Gough (2007) and the Critical Appraisal Skills Programme (*CASP Checklists - Critical Appraisal Skills Programme*, n.d.). Following appraisal, one article, (McPoland et al., 2017) was deemed not to reach the criteria for inclusion in the current study due to the lack of data provided, leaving nine articles in the current literature review (see Appendix B). Table 2.1 sets out the aims and methods of each of the nine included studies.

Table 2.1

Details of articles included in the literature review

Article Title & Author(s)	Year	Aim(s) of study	Design and Methods
A relational understanding of sibling experiences of children with rare life-limiting conditions: Findings from a qualitative study. Malcolm et al.	2014	To report sibling experiences related to rare degenerative and progressive conditions to inform the future development of supportive interventions.	Qualitative: semi-structured interviews including card sort with 8 siblings of children with rare degenerative life limiting conditions; grounded theory used for data analysis and theory generation.
Children and young people's experiences of having a sibling with complex health needs: a literature review. Grant et al.	2022	To examine the experiences of siblings growing up with a brother or sister with complex health needs and how this affects their lives.	Literature review using population, exposure, outcome framework; thematic analysis used to group findings and identify main themes of nine included studies.
Living with a child who has a life-limiting condition: The functioning of well-siblings and parents. Jaaniste, Cuganesan et al.	2022	To examine the self-reported psychosocial functioning (namely the psychological, social and school functioning) of well siblings who have a brother or sister with a life limiting condition.	Quantitative: self-report and parent proxy report using the Pediatric Quality of Life Inventory (Varni et al., 2001) to assess emotional, social and school functioning of siblings of children with a life limiting condition.

Paediatric life-limiting conditions: Coping and adjustment in siblings. Brennan et al.	2012	To answer the research question: ‘what are the experiences of siblings of children with life-limiting conditions and how do they cope with those experiences?’	Qualitatively driven, longitudinal mixed methods approach including standardised psychometric measures and visual, participatory qualitative methods; analysis using grounded theory approach.
Parent and well sibling communication in families with a child who has a life-limiting condition: Quantitative survey data. Jaaniste, Chin et al.	2022	To determine the amount of illness-related communication between parents and well siblings; to determine the predictors of amount of illness-related information provided to well siblings; to elicit a broader picture of communication patterns within families caring for a child with an LLC; to determine factors associated with sibling-rated satisfaction with familial communication; and to establish which familial communication variables were associated with sibling functioning.	Quantitative: self-report and parent report. Measures were the Parent-Sibling Communication Measure (D. S. Cohen et al., 1989); the Family Communication Scale (Olson et al., 2004); the Family Environment Scale (Moos & Humphrey, 1974); the Pediatric Quality of Life Inventory (Varni et al., 2001); the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995); and the Child/Youth Resilience Measure (Liebenberg et al., 2013).
Grief Related to the Experience of Being the Sibling of a Child With Cancer Nolbris et al.	2014	To describe siblings’ thoughts about grief related to the experience of having a brother or sister with cancer.	Qualitative content analysis, open-ended interviews
Siblings caring for and about pediatric palliative care patients Gaab et al.	2014	To identify the concerns of siblings of pediatric palliative care (PPC) patients.	Qualitative semi-structured interviews analysed using qualitative inductive thematic analysis.

Adolescent siblings of children with cancer: A qualitative study from a salutogenic health promotion perspective. Løkkeberg et al.	2020	To explore the experiences of adolescents with a sibling suffering from cancer from a salutogenic health promotion perspective.	Qualitative semi-structured interviews analysed using qualitative content analysis
Emotional Experiences Among Siblings of Children with Rare Disorders Haukeland et al.	2015	To explore the emotional experiences of siblings as expressed by participants during group sessions, and to identify relevant themes for interventions targeted at siblings.	Qualitative thematic analysis of 20 sessions with 11 different support groups for siblings of children with rare disorders that occurred in a natural setting.

2.4 Research findings.

2.4.1 Thematic synthesis

The research findings underwent a process of thematic synthesis to help collate, present and critique findings relevant to the research question across the included studies (Booth et al., 2016). As Thomas and Harden (2008) point out, deciding which data to extract from qualitative studies is less straightforward than from randomized control trials, and involves a certain degree of subjectivity. Therefore, the findings presented in the thematic synthesis should be read in the light of the reflexive statements made in the opening chapter of the current study.

Following Campbell et al. (2003) and Booth et al. (2016), the key concepts were derived from the results section of each article and summarized in a table, then colour-coded line by line based on tentative themes (see Appendix C). Next, the free codes were converted to descriptive themes (see Appendix D) and finally analytical themes were developed in order to present the findings related to the initial review question (Booth et al., 2016, p. 227). This step is described by Thomas and Harden (2008) as *going beyond* the findings of the original articles in the literature review and entails generating new ideas and/or hypotheses.

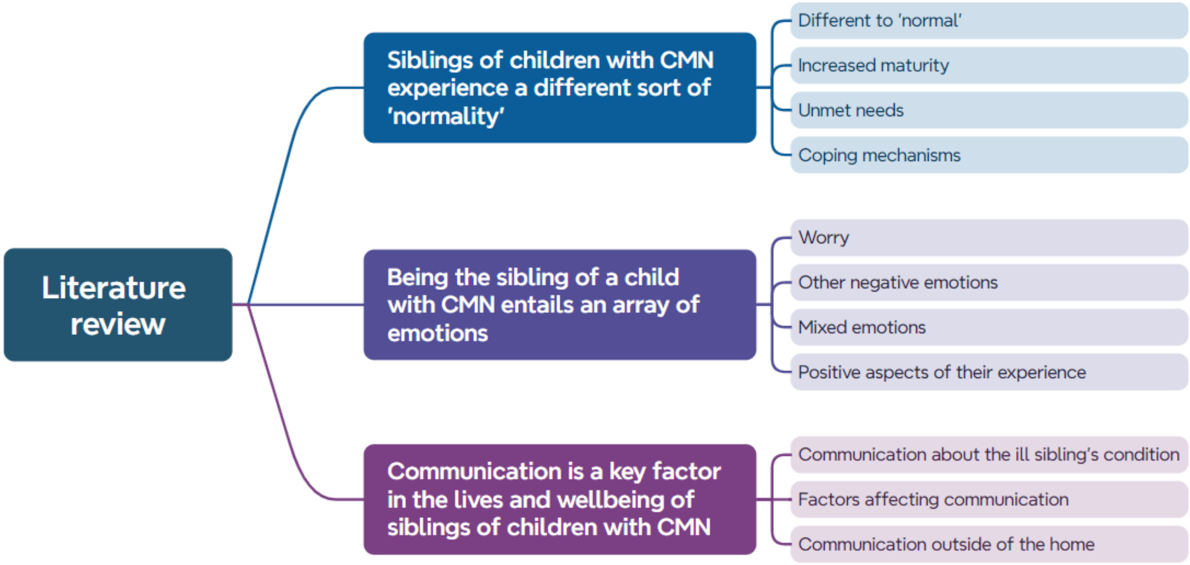
The findings of the current literature review led to the development of the following analytical themes:

i. Siblings of children with CMN experience a different sort of 'normality'.
ii. Being the sibling of a child with CMN entails an array of emotions.
iii. Communication is a key factor in the lives and well-being of siblings of children with CMN.

Figure 2.1 presents the analytical themes and sub-themes derived from the literature review.

Figure 2.1

Analytical themes and sub-themes derived from the literature review



In the following section, the findings from the literature review are explored by analytical theme and sub-theme.

2.4.2 Siblings of children with CMN experience a different sort of 'normality'.

2.4.2.1 Different to 'normal'. The findings from the literature review indicated that well siblings perceived their lives to be different from the lives of most of their peers (Haukeland et al., 2015). Some were able to accept this difference as a sort of *new normal* (Grant & McNeilly, 2022), while others had a more negative response, including feeling like they were missing out or feeling frustrated (Haukeland et al., 2015). Siblings also recognised that they were treated differently to their ill sibling, not only by their parents but also by grandparents and people outside of the family (Haukeland et al., 2015).

Differences reported by siblings of children with CMN included being used to frequent cancellation or changes to plans (Grant & McNeilly, 2022), feeling they were missing out on doing 'normal' activities with their siblings (Haukeland et al., 2015), that limitations were put on their family or social life (Malcolm et al., 2014) and that they were unable to have a 'normal' relationship with the ill sibling (Brennan et al., 2012). Furthermore, families with a child with CMN had to take precautions to avoid infections and this could be a source of frustration for well siblings (Løkkeberg et al., 2020). This is likely to have been particularly pronounced during the COVID-19 pandemic when children and young people with complex medical needs are likely to have been considered at 'high risk', meaning their families would have needed to take considerable precautions to ensure the ill child did not contract the virus (*Who Is at High Risk from Coronavirus (COVID-19)*, 2021).

Despite feelings of difference, well siblings were able to identify benefits of their situation, such as being able to play around with special aids that the ill child had, e.g. a wheelchair, while some well siblings were able to reflect on their own and their family's coping resources (Haukeland et al., 2015), indicating an increased level of maturity compared to their peers. Nevertheless, the differential treatment between themselves and their brother or sister with CMN evoked negative feelings in some well siblings, with one participant reflecting, "it is like a very big part in my life that is being used by her" (Haukeland et al., 2015, p. 715).

2.4.2.2 Increased maturity. As a result of their experiences, siblings demonstrated an increase in responsibility and maturity compared to their peers. For example, well siblings wanted to be involved in the care of their brother or sister with CMN (Gaab et al., 2014; Grant & McNeilly, 2022). This gave them a sense of purpose and pride, and helped them to feel involved in the family unit (Malcolm et al., 2014). This increase in maturity encompassed other aspects of the siblings' lives outside of the home. For example, well siblings of children with CMN often acted as a peacemaker among friends (Brennan et al., 2012) and demonstrated greater compassion and empathy towards others than did their peers (Haukeland et al., 2015; Malcolm et al., 2014). Thus, having a brother or sister with CMN may result in well siblings developing skills and strategies that enable them to get along better with others and facilitate positive relationships.

Nevertheless, this maturity and compassion often came at a price. Some well siblings felt partly responsible for their ill sibling's wellbeing (Nolbris et al., 2014). Others were aware of negative attitudes and unkindness towards the ill sibling (Malcolm et al., 2014). Such attitudes and behaviour could drive well siblings to actively avoid being seen in public with their brother or sister (Grant & McNeilly, 2022). On the other hand, siblings felt a sense of accomplishment when they completed activities as a family (Grant & McNeilly, 2022) and took pride in the role they played in caring for the ill child (Malcolm et al., 2014). Furthermore, Løkkeberg et al. (2020) deemed siblings to particularly appreciate being healthy themselves, and the good health of other family members as a result of having a brother or sister with CMN.

2.4.2.3 Unmet needs. The *new normal* that siblings experience could result in their own needs being left unmet. Well siblings were found to lack attention from their parents (Brennan et al., 2012) and at times felt unimportant, forgotten or even abandoned (Nolbris et al., 2014). Siblings did not always feel they had someone to talk to about their thoughts and feelings (Nolbris et al., 2014) and teachers did not know how best to treat siblings when they became upset at school (Løkkeberg et al., 2020).

One study reported that siblings deprioritised their own needs and kept their emotions to themselves (Brennan et al., 2012), suggesting that they did not feel able to talk to anyone inside or outside of the home about their feelings. What is more, in a quantitative study into the functioning of well siblings and their parents, well siblings were found to have significantly poorer self-reported emotional, social and school functioning compared with normative data (Jaaniste, Cuganesan, et al., 2022). Well siblings' resilience was found to be a protective factor (Jaaniste, Cuganesan, et al., 2022).

Another study found that siblings desired to be part of a group where they could feel 'normal', that is, where they had shared lived experiences (Grant & McNeilly, 2022). In reality, these groups were rare and met infrequently (Malcolm et al., 2014). Nolbris et al. (2014) affirmed that well siblings required support throughout their brother or sister's illness and possible death to help them process their emotions and recognise that their feelings were normal for someone in their situation. Similarly, Jaaniste, Cuganesan et al. (2022) maintain that palliative care should be holistic and family-centred, addressing the needs not only of the ill sibling but also those of well siblings. Unfortunately, findings from the literature review suggested that such support was sparse.

2.4.2.4 Coping mechanisms. The use of coping mechanisms appeared to be an important part of the lived experiences of siblings of children with CMN. In order to cope with their circumstances, siblings sought refuge in activities outside of the home such as school, music and sport (Grant & McNeilly, 2022) or working out and listening to music (Haukeland et al., 2015). For others, being involved in the care of their ill sibling was a source of comfort (Gaab et al., 2014) as was speaking to close friends (Grant & McNeilly, 2022) or family (Jaaniste, Chin, et al., 2022). The ability to compartmentalise their home and school lives was repeatedly found to help siblings cope (Brennan et al., 2012; Grant & McNeilly, 2022; Nolbris et al., 2014).

Coping strategies were categorised in different ways by the various authors of studies involving the siblings of children with CMN. Haukeland et al. (2015) and Gaab et al. (2014) described *active* coping strategies, such as talking to someone or exercising. Haukeland et al. (2015) contrasted these with *passive* coping strategies, including trying one's best to accept the situation. Another study reported that siblings used *avoidant* strategies, for example, distraction, resignation or social withdrawal, to help cope with having a brother or sister with CMN (Brennan et al., 2012). Meanwhile, Løkkeberg (2020) described *positive* coping strategies as those who employed prayer and belief in a good outcome, or shutting out fears of a bad outcome.

2.4.2.5 Summary. Findings from the literature review suggested that siblings of children with CMN had certain unique, shared lived experiences. They were aware of the difference between their own home lives and those of their peers who they deemed to live ‘normal’ lives. Whilst their own needs may have gone unmet, siblings adjusted to their situation, their *new normal*, by developing a certain emotional maturity and employing coping mechanisms, such as engaging in activities outside of the home, or talking to trusted others. At times, siblings also felt that they were missing out on ‘normal’ relationships and experiences, as well as having to manage feelings of frustration and embarrassment.

2.4.3 Being the sibling of a child with CMN entails an array of emotions.

2.4.3.1 Worry. Feelings of worry and anxiety featured prominently in the literature relating to the lived experiences of siblings of children with CMN. Malcolm et al. (2014) reported that worry pervades the lives of siblings and can have a negative impact on their schoolwork and social lives. Well siblings worried about death (Haukeland et al., 2015) and these feelings were particularly acute immediately after their brother or sister’s diagnosis (Nolbris et al., 2014). Furthermore, well siblings continued to worry about their sibling’s health even after treatment had finished due to the risk of relapse (Løkkeberg et al., 2020).

Siblings were also aware of how their own feelings of worry could affect other family members (Malcolm et al., 2014). This could lead them to try to hide their feelings so as not to have a negative impact on others in the family.

On a more positive note, siblings in one study demonstrated a determination to live in the present, thus avoiding rumination about the past and future (Brennan et al., 2012). This suggests that ‘mindfulness’ techniques (Kabat-Zinn, 2003), whether wittingly or unwittingly employed, may help siblings to deal with everyday life and the difficult emotions that arise.

2.4.3.2 Other negative emotions. Well siblings experienced a range of negative emotions as a result of having a brother or sister with CMN, including frustration (Grant & McNeilly, 2022), anger (Gaab et al., 2014), helplessness (Nolbris et al., 2014) and sadness (Haukeland et al., 2015). Two studies found that siblings experienced feelings of jealousy due to the amount of attention their ill sibling received (Grant & McNeilly, 2022; Løkkeberg et al., 2020), whereas jealousy was invoked when siblings compared themselves to other families in Haukeland et al.’s (2015) study. For others, such comparisons led to feelings of frustration and the belief that they were missing out on family life as a result of their brother or sister’s condition (Grant & McNeilly, 2022).

The research suggested that well siblings’ feelings about their situation changed over time. The time of diagnosis was a particularly challenging period for well siblings who found the experience scary and painful (Løkkeberg et al., 2020). Grant and McNeilly (2022) found that the emotional and behavioural issues of well siblings increased as well siblings got older and their understanding of the illness and their ability to cope with it changed. Additionally, Nolbris et al. (2014) reported that well siblings continued to experience sadness long after diagnosis and even after successful completion of treatment, although family members may not have been aware. In the event of a sibling’s death, grieving could help to give meaning to the bond between the ill and well siblings (Nolbris et al., 2014).

2.4.3.3 Mixed emotions. Although research into the experience of siblings of children with complex medical needs was dominated by reports of negative emotions, these were at times presented alongside more positive aspects, demonstrating the mixed emotions experienced by well siblings. For instance, one study described the experience of living with a sibling with a rare or severe disorder as enriching for well siblings, in addition to the more negative emotions they experienced (Haukeland et al., 2015). Furthermore, siblings' sadness at being informed of the diagnosis was mixed with a sense of relief (Haukeland et al., 2015). Another study described the mixed emotions of well siblings which included jealousy, frustration and happiness (Grant & McNeilly, 2022). Reactions to ill siblings' deviant behaviour ranged from not being bothered to feeling embarrassed, angry and irritated (Haukeland et al., 2015), indicating that well siblings reacted to their situation in a variety of ways.

2.4.3.4 Positive aspects of their experience. As well as reports of mixed emotions, the research included in the current review highlighted positive aspects of well siblings' experiences. Siblings were found to take pride in caring for their brother or sister (Malcolm et al., 2014) and to derive a sense of purpose and feelings of self-worth from their responsibilities, with 70% of siblings scoring above average levels on the Harter Self-Perception Profile (Brennan et al., 2012). Reciprocated care by the ill sibling was a source of positive emotions for well siblings (Haukeland et al., 2015). Moreover, siblings felt a sense of accomplishment from completing activities as a family (Grant & McNeilly, 2022), an experience that may be taken for granted by their peers. Løkkeberg et al. (2020) reported that siblings described that having a brother or sister with CMN made them stronger and more resilient than they were previously, and that they gained an increased ability to understand others. Haukeland et al. (2015) also reported siblings' ability to derive positives from difficult situations, for example, siblings' reflecting on their own coping resources when faced with incidents of bullying.

2.4.3.5 Summary. Existing research indicated that well siblings experienced a range of emotions as a result of having a brother or sister with CMN. These emotions were predominantly negative, with feelings of worry pervading their existence. The time of diagnosis was particularly stressful for well siblings, but feelings of worry and sadness continued, including once treatment had ceased. Nevertheless, well siblings were able to derive positives from their situation and appreciated aspects of their lives, such as activities as a family, that their peers did not necessarily appreciate to the same extent. Furthermore, feelings of self-worth and empathy appeared to be particularly high among well siblings, potentially as a result of being involved in the care of their brother or sister.

2.4.4 Communication is a key factor in the lives and wellbeing of well siblings.

2.4.4.1 Communication about the ill sibling's condition. Research suggested that communication about an ill sibling's condition was an important factor in the lives of well siblings. Being informed about the ill sibling's condition was important to well siblings (Grant & McNeilly, 2022) and resulted in them being more patient and accepting of the brother or sister with CMN (Gaab et al., 2014). Conversely, a lack of communication about the ill siblings' condition could cause anger and fear in well siblings (Gaab et al., 2014). Siblings generally wanted to be well informed about their ill sibling's health, including when they were close to death, but did not want every conversation to be dominated by it (Gaab et al., 2014). According to Nolbris et al. (2014), communication with the well sibling following the diagnosis of an ill child tended to focus on treatment; the potential early death of the sibling was rarely discussed with them.

Grant and McNeilly (2022) found that some siblings had a preference for talking to their peers rather than adults, whereas others felt better understood by adults. In another study, siblings were found not to communicate their worries to their parents to avoid over-burdening them (Malcolm et al., 2014). With regard to communication generally, well siblings and their parents in families with a child with CMN were found to be significantly more satisfied with familial communication relative to published norms (Jaaniste, Chin, et al., 2022).

Furthermore, it was reported that 89.2% of parents were either mostly or somewhat satisfied with the amount of information they had shared with the well sibling about the ill sibling's condition (Jaaniste, Chin, et al., 2022). However, Malcolm et al. (2014) discovered that well siblings tended to know more about the condition than their parents thought they did, suggesting that siblings may not be have been content with the information provided by their parents or health professionals and therefore sought it through other means, such as the internet.

2.4.4.2 Factors affecting communication. The well sibling's age and parents' resilience resources, as measured by the parent version of the Child/Youth Resilience Measure (Liebenberg et al., 2013) were the strongest predictors of the amount of illness-related information provided to well siblings (Jaaniste, Chin, et al., 2022). This finding suggests that parents more readily provide information to well siblings as they get older, possibly because of their increased understanding and awareness of the situation. In addition, parents with greater resilience resources may feel better able to cope with the well sibling's response and potential questions about their brother or sister's illness, and therefore, are more willing to share information.

In families with a child with a life-limiting condition, familial cohesion was the only factor that correlated with well siblings' satisfaction with general familial communication, but it was not clear whether familial cohesion led to greater satisfaction with communication, or vice versa (Jaaniste, Chin, et al., 2022). Jaaniste, Chin et al. highlighted that the amount of illness-related communication that well siblings wished to receive varied depending on the individual and some may find it unhelpful or distressing. One factor that may have affected this was gender: female well siblings were found to communicate significantly more about their ill sibling than did male well siblings (Jaaniste, Chin, et al., 2022), suggesting that boys were less likely to talk to their parents about their ill sibling's health than girls.

It is noteworthy that there was no significant correlation between the well sibling's social and school functioning with any familial communication variables. This would seem to imply that the amount, type and level of satisfaction with communication has little bearing on siblings' wellbeing and functioning outside of the home. Given the importance of communication for well siblings, this finding is somewhat surprising, and may benefit from further exploration using qualitative methods.

2.4.4.3 Communication outside of the home. Many well siblings attempted to compartmentalise their lives by avoiding talking about their ill sibling outside of the home (Brennan et al., 2012; Grant & McNeilly, 2022). Løkkeberg et al. (2020) reported that some well siblings found it too difficult to explain to their friends, while others refrained from sharing their thoughts and feelings because they felt that their friends would not understand. Others still did not want to bother their friends and worried about pushing them away by talking about their brother or sister with CMN (Løkkeberg et al., 2020). For well siblings, trying to make others understand them could be stressful and when friends said they understood, but in reality did not, well siblings experienced even greater feelings of loneliness and sadness (Løkkeberg et al., 2020).

Conversely, well siblings valued friends who visited or prayed for their ill sibling (Gaab et al., 2014). It was reported that being active with friends could help well siblings take their mind off the disease (Løkkeberg et al., 2020) and they chose to spend time with friends to help them through the grieving process (Nolbris et al., 2014). Nolbris et al. (2014) asserted that well siblings of all ages needed someone who could understand them, listen to them and allow them to speak their mind without worrying about how the other person might feel. While talking to their friends about the ill sibling could provide a source of support for some, for others it appeared to be an additional source of stress.

Similarly, informing the whole class about the sibling’s illness could aid understanding among the well sibling’s peer group (Løkkeberg et al., 2020). However, some did not want to share this information with their class because they did not want their identity to be defined by being the sibling of a child with CMN, and wanted everything to stay “as normal as possible” (Løkkeberg et al., 2020, p. 8). For others, ensuring teachers were aware of their home situation meant that they could make themselves available to siblings, adapt schoolwork and lower requirements during difficult periods (Løkkeberg et al., 2020). It may be helpful to explore further the role teachers may play in supporting well siblings and whether lowering requirements, such as reducing the amount of homework they need to complete while the child with CMN is in hospital, could help well siblings to cope, taking into account the long-term benefits or disadvantages this may have.

2.4.4.4 Summary. Findings from the literature review suggested that well siblings wished to be informed and kept updated about their sibling’s condition, but the frequency of such communication needed to be carefully managed. Factors such as parental resilience and the child’s gender may have affected how much information they were given, and those who did not feel they had enough information may seek to gain it in ways other than talking to their parents.

While some well siblings were comfortable talking about their ill brother or sister to friends or classmates, some preferred to compartmentalise home and school life. The decision to share information with peers was an individual one and it was advisable to leave it up to well siblings to make the decision. When schools were informed that a child had a sibling with CMN, teachers could make reasonable adjustments to help support them. It would be helpful to explore further what that support may look like by asking well siblings themselves.

2.4.5 Findings of excluded study

Following the critical analysis of articles using the MMAT (Hong et al., 2018), the decision was made to exclude the McPoland et al. (2017) poster extract from the literature review as it contained sparse information about the study. Nevertheless, it was felt that the findings were of relevance to the current study and therefore it was important to outline them within the current chapter.

McPoland et al. (2017) undertook semi-structured interviews with children receiving paediatric palliative care and their siblings from two paediatric hospitals: one in Akron, Ohio, and the other in Port-au-Prince, Haiti. This approach was unique in comparing and contrasting the views of children and young people located in two different countries and cultures. The study found that the Haitian children had a greater exposure to death and focused on their faith in order to understand their experiences (McPoland et al., 2017). This suggests that the findings of the articles included in the literature review may be, at least partly, culture-specific and it would be wise to avoid overgeneralising them. Furthermore, it is important to acknowledge any socio-economic and cultural factors which may affect responses from participants in the current study.

2.4.6 Overview of Findings

Findings from the thematic synthesis indicated that siblings of children with CMN perceived their lives to be different to those of their peers and found it helpful to meet others in a similar situation, to help them feel understood. Furthermore, siblings experienced myriad emotions, including high levels of worry and anxiety, as a result of having a brother or sister with CMN. Communication was an important factor in helping siblings understand the situation. Currently, there appears to be a lack of support for well siblings, and they often feel unable to speak about how they are feeling to their parents and other adults.

To help them cope with their experiences, well siblings used strategies such as compartmentalising, whereby they ‘parked’ their worries about their ill sibling and focused on other things. School could be a source of stress but also a haven away from the difficulties experienced at home. Other than this, there were little in the way of findings about well siblings’ experience of school or the interaction of school and family life.

2.4.7 Strengths, limitations and gaps in the literature

The existing literature comprised studies which used a variety of methods to investigate the experiences of siblings of children with CMN, including qualitative (e.g. Malcolm et al., 2018), quantitative (e.g. Jaaniste, Chin, et al., 2022) and mixed methods (e.g. Brennan et al., 2012). The qualitative studies employed a variety of methodologies ranging from thematic and content analysis to grounded theory and participatory methods; notably, none of them used IPA. Among the quantitative studies, self- and parent-report questionnaires were used, including the Parent-Sibling Communication Measure (D. S. Cohen et al., 1989) and the Pediatric Quality of Life Inventory (Varni et al., 2001).

While the literature broadly focused on the siblings of children who would be classed as having CMN according to the definition employed by the current study, none of the studies used this term, with most focusing on a specific subset of such children. For example, studies focused on the siblings of children with cancer (Nolbris et al., 2014), children with life limiting conditions (Malcolm et al., 2014) and pediatric palliative care patients (Gaab et al., 2014). Furthermore, with the exception of one quantitative study (Jaaniste, Cuganesan, et al., 2022), the research did not explore the well siblings' school experience. Instead, they sought to describe well siblings' thoughts about grief, identify their concerns, and find out how well siblings coped with their experiences more generally. Thus, the existing literature focuses on the emotional experiences of well siblings, communication within the family and the differences between their lived experiences and those of their peers. It appears that there has been little exploration of the impact of having a sibling with CMN on a child's school experience and vice versa, particularly using qualitative methods. Furthermore, IPA has not yet been employed to explore siblings' experiences, and well siblings have never previously been asked to conceptualise their ideal school.

The current study aims to plug this gap by asking well siblings themselves about the interplay of their experience of family and school lives, and by exploring how they envisage their ideal school using IPA. It is hoped that by seeking the views of siblings of children with CMN directly, the findings of the current study will lead to guidance and/or recommendations that may influence how schools and EPs support and engage with well siblings to ensure they have the best possible experience given the circumstances.

2.4.8 Research questions

Based on the gaps identified in the existing literature, the current research seeks to answer the following questions:

- RQ1: What are the lived experiences of siblings of children with CMN?
- RQ2: How do siblings of children with CMN experience family life?
- RQ3: How do siblings of children with CMN experience school?
- RQ4: How do siblings of children with CMN envisage their ideal school?

2.5 Chapter summary

In this chapter, the search strategy for the literature review was set out, the articles included were appraised, and the findings using thematic synthesis were presented. The following themes emerged: i) Siblings of children with CMN experience a different sort of 'normality'; ii) Being the sibling of a child with CMN entails an array of emotions; and iii) Communication is a key factor in the lives and well-being of siblings of children with CMN. Once the findings had been presented, gaps in the literature were identified, principally, the lack of research into well siblings' school experience and views on how school staff may best support them. This led to the development of the research questions posed by the current study which aims to explore the lived experiences of siblings of children with CMN. In particular, it seeks to explore how well siblings' home and school lives affect one another, and the ways in which teachers and EPs may be able to support well siblings. The proceeding chapter sets out the methodology used in this study.

Chapter 3: Methodology

3.1 Chapter outline

The previous chapter presented the findings from existing research into the lived experiences of siblings of children with CMN. It set the scene for the current chapter by identifying gaps in the literature, namely, the ways in which siblings' school experiences affect their home life and vice versa, and how schools may best support siblings of children with CMN. This chapter presents the researcher's position, the research design, data collection methods, ethical considerations and participant characteristics for the current study into the lived experiences of siblings of children with CMN.

3.2 Methodological orientation

This section sets out the research paradigm and the researcher's ontological and epistemological standpoint in relation to the current study.

3.2.1 Research paradigm

The research paradigm has been defined as "the basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways" (Guba & Lincoln, 1994, p. 105). The current study adopts a constructivist, also known as interpretive or naturalistic, paradigm, as it seeks to understand the phenomena being studied from the point of view of those who experience it (Robson, 2002). That is, it seeks to explore the lived experiences of siblings of children with CMN by giving them a platform to recount their own experiences, all the while recognising the subjectivity of both participants and the researcher. It rejects the positivist stance that value-free facts can be accessed through direct observation or experience, and that every scientist researching a given phenomenon would obtain the same result (Robson, 2002). Furthermore, it rejects the post-positivist stance that there is a single truth which can be uncovered by controlling for subjective influences (Robson, 2002). Instead, the constructivist paradigm posits that knowledge is created through discourses and systems of meaning (Braun & Clarke, 2013). Constructivist researchers aim to uncover the "multiple social constructions of meaning and knowledge" (Robson, 2002, p. 27), working together with the research participants to co-create this reality. Given the constructivist paradigm framing the research, it follows that a qualitative approach, using semi-structured interviews, is most suitable for eliciting the experiences of its participants.

3.3 Ontology and epistemology

Ontology has been defined as "what actually exists in the world about which humans can acquire knowledge" (Moon & Blackman, 2014). On one side of the ontological scale, a realist stance holds that a single reality exists independent of human experience and this reality can be researched and understood by researchers (Moon & Blackman, 2014). On the other side, a relativist holds that reality is constructed by the human mind and no single reality exists outside of it, but rather, reality is relative according to the individual experiencing it (Moon & Blackman, 2014).

In line with the constructivist paradigm, the current research takes a critical realist ontological position, which posits that knowledge can only be accessed through the subjective lens of the knower (Braun & Clarke, 2013). Critical realism holds that there is an external reality independent of human thought and knowledge, but it is "only imperfectly apprehendable because of basically flawed human intellectual mechanisms and the fundamentally intractable nature of phenomena" (Guba & Lincoln, 1994, p. 110). That is, although a real world exists outside of human conscience, our ability to know about it is determined by social constructions and is therefore fallible (Bygstad & Munkvold, 2011). In the current research, it is crucial that the researcher acknowledges her own subjectivity, which affects the way in which she interprets the data, as well as appreciating that the participants' narratives are subjective and may not reflect the experience of all siblings of children with CMN.

Nevertheless, it is likely that there are some commonalities between participants and other siblings of children with CMN, and the research, with its critical realist stance, may provide "an impetus for change" (Robson, 2002, p. 41) if misunderstandings and actions based on them surface during the research. While the primary aim of this study is exploratory, it is possible that there may be an emancipatory element to the research, whereby the findings could lead to changes in school and EP practices to better support siblings of children with CMN.

Epistemology has been described as being "about the nature of knowledge, and addresses the question of what it is possible to know" (Braun & Clarke, 2013, p. 46). The current study takes a subjectivist epistemological position, which holds that there is no one true reality, as in an objectivist epistemology, but rather "[p]eople impose meaning and value on the world and interpret it in a way that makes sense to them" (Moon & Blackman, 2014, p. 6). Thus, the current study seeks to understand the experience of being the sibling of a child with CMN from the point of view of the siblings themselves. The study also seeks to determine the commonalities between the experiences of several siblings, all the while recognising and acknowledging that their experiences are presented through the researcher's own lens.

3.4 Interpretative phenomenological analysis

IPA is especially useful as an approach for research that is concerned with a particular experience (J. Smith et al., 2012). It is a qualitative method which examines how people make sense of important life experiences (J. Smith et al., 2012). IPA aims to engage with reflections on experiences that are of great significance to the person experiencing them (J. Smith et al., 2012). It has largely been used in health psychology and in the analysis of data from semi-structured interviews (Brocki & Wearden, 2006). In research employing IPA, it is important that participants are able to express themselves in their own words (Brocki & Wearden, 2006). Semi-structured interviews allow for this by providing the flexibility for the researcher to ask follow-up questions based on previous responses while loosely guiding the participant to reflect on the relevant experience.

IPA is concerned with "where ordinary everyday experience becomes 'an experience' of importance as the person reflects on the significance of what has happened and engages in considerable 'hot cognition' in trying to make sense of it" (J. Smith et al., 2012, p. 33). In the current study, by asking well siblings directly about their experiences, their everyday lives become "an experience of importance" (J. Smith et al., 2012, p. 33), rather than taken for granted, as they may otherwise be. Hence, IPA is considered to be particularly appropriate for analysing the accounts of siblings of children with CMN as they reflect on the ways in which having a brother or sister with CMN affects family and school life.

To better understand the foundations and purpose of IPA research, it is important to understand the philosophical concepts which underpin it: phenomenology, idiography and hermeneutics (J. Smith et al., 2012).

3.4.1 Phenomenology

Phenomenology has been described as “the study of structures of consciousness as experienced from the first-person point of view” (D. W. Smith, 2018). Phenomenology became a discipline in its own right in the early 20th century with the works of philosophers including Husserl, Heidegger, Sartre and Merleau-Ponty (D. W. Smith, 2018). Despite differences in emphasis, common to all phenomenologists is an interest in the experience of being human (J. Smith et al., 2012).

According to Husserl, phenomenology requires us to focus our gaze inwards and reflect on our subjective experiences of phenomena (J. Smith et al., 2012). In everyday life, we have a tendency to take our experiences for granted as we engage in everyday activities. In order to be phenomenological, we must take a step back from our activities and attend to our experience of the world (J. Smith et al., 2012). Husserl was also interested in what was at the core of the subjective experience of a given phenomenon and in establishing its essential features in a process named “eidetic reduction” (J. Smith et al., 2012, p. 14).

It is noteworthy that not everyone agrees that IPA is a phenomenological methodology. Van Manen (2017) argues that IPA is not phenomenological but rather psychological in its approach, claiming that it focuses on the participant’s experience of the phenomenon as opposed to the phenomenon itself. The current research is underpinned by the view that IPA is both phenomenological and psychological in its approach (J. Smith et al., 2012). That is, it is concerned with “an individual’s personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself” (J. A. Smith et al., 1999, p. 218). Therefore, IPA consciously rejects the philosophical aim of phenomenology of going “back to the things themselves” (Husserl, 1927, cited in Smith et al., 2009, p.12) and knowingly focuses on a particular experience, which, in essence, relies on the account of the person or people who have experienced it. Rather than excluding it as a phenomenological approach, the researcher upholds the belief that IPA straddles both psychological and phenomenological realms (J. Smith et al., 2012).

3.4.2 Hermeneutics

Hermeneutics is described as the theory of interpretation (J. Smith et al., 2012). Its origins can be traced back to the interpretation of biblical texts (Eatough & Smith, 2017). Heidegger and Gadamer, two of the key hermeneutics theorists, stressed the importance of situating a text in its historical and cultural context as we attempt to understand it (Langdridge, 2007). Gadamer also highlighted the importance of speech and conversation as being at the heart of all of our understanding of the world (Langdridge, 2007).

IPA requires the researcher to make sense of participants making sense of their experience, and therefore involves a double hermeneutic (J. Smith et al., 2012). Thus, the researcher is one step removed from the experience as they can only access the experience through the participants’ accounts of it (J. Smith et al., 2012). According to Schleiermacher, another key theorist in the field, this is part of the art of interpretation, and enables the interpreter to understand the utterer “better than he understands himself” (Schleiermacher, 1998, p. 266). While it is not claimed that the researcher will understand the participants of the current study better than they do, it is hoped that through this research, she will be able to “offer meaningful insights which exceed and subsume the *explicit* claims of our participants” (J. Smith et al., 2012, p. 23).

3.4.3 Idiography

IPA involves the detailed examination of a particular experience for a certain group of people and is therefore an idiographic approach (J. Smith et al., 2012). In contrast, most psychological endeavours are concerned with the generalisability of accounts of human behaviour and are therefore nomothetic (J. Smith et al., 2012). According to Harré (1980), idiography uses a different method of establishing generalisations, rather than rejecting generalisations altogether. That is, IPA "typically employs small participant groups who share experience of a particular phenomenon and aims to elucidate shared patterns of meaning" (Thackeray & Eatough, 2015, p. 271). As Smith et al. (2012) explain, IPA is committed to both the detail and depth of analysis, and how a particular experience is understood by particular people, in a given context. This is another reason that IPA was deemed the most suitable approach to study the experiences of siblings of children with CMN as it allows the researcher to delve into the experiences of a small sample and identify the individual and collective experiences of participants (J. Smith et al., 2012).

3.4.4 Characteristics of IPA

Bracketing and reflexivity are employed in IPA research to ensure the results are trustworthy and rigorous (Rettke et al., 2018) and are therefore, "worth paying attention to" (Lincoln & Guba, 1985, p. 290).

3.4.4.1 Bracketing. Husserl introduced the idea of bracketing to phenomenology as a means of separating "the taken-for-granted world in order to concentrate on our perception of that world" (J. Smith et al., 2012, p. 13). Likewise in research, it is important for researchers to be able to separate their taken-for-granted preconceptions as far as possible to ensure the research is trustworthy (Rettke et al., 2018). Bracketing is used in IPA research to “mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the project” (Tufford & Newman, 2012, p. 2). Thus, bracketing allows the researcher to acknowledge their preconceptions and the potential influence these may have on their interpretation of the data. It is also important for the researcher to *bracket off* their own views and experience during the interview process so as not to allow any preconceived ideas to affect their questioning of participants which could in turn lead to the data collected being skewed (J. Smith et al., 2012). To this end, throughout the research, the researcher kept a reflective diary to help bracket off any preconceived ideas Isgehad and reflect on how these may have affected the research process prior to interviewing, during interviews and afterwards, at the analysis stage (Wall et al., 2004).

3.4.4.2 Reflexivity. Robson (2002) stresses the importance of reflexivity in phenomenological research to mitigate the effects of researcher bias, which can affect every aspect of research from the participants selected to the reporting and analysis of findings. Finlay and Gough (2008) set out that reflexivity requires the researcher to be critically reflective about how their own social background, assumptions, positioning and behaviour may affect the various aspects of the research process. Rather than aiming to be objective, the researcher should aim to be reflexive, that is, putting aside personal feelings and preconceptions, since “it is not possible for researchers to set aside things about which they are not aware” (Ahern, 1999, as cited in Robson, 2002, p. 172). Keeping a research diary allowed the researcher to be reflexive throughout the research journey, ensuring that she was honest with herself about any preconceptions she may have had and helping her to make decisions which stay true to the theoretical underpinnings of IPA. For example, during interviews, bracketing helped the researcher to ensure that interviews were treated independently and did not carry information from one to the next that might skew or influence a participant's responses.

3.5 Outline of research design

This section outlines the process for conducting the research including gaining ethical approval, sampling and recruitment procedures.

3.5.1 Research process and ethical approval

In order to gain ethical approval, an application was made to the University of East London on 14th January 2022 (see Appendix E) and approval with minor amendments was granted on 1st February 2022 (see Appendix F). An application to amend the original application was made on 11th September 2022 to allow interviews to be carried out in the participants' homes and to extend the potential age range of participants from between 11 and 18 to between 10 and 19[3] (see Appendix H). The amended application was approved on 21st September 2022. The recruitment process commenced in April 2022. Due to unforeseen circumstances which led to the researcher intermitting her studies for a year, the recruitment process was paused in October 2022 and recommenced in October 2023. Data collection began in November 2023 and all interviews were completed by December 2023.

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[3] It was later noted that the title on the Ethics Amendment Request Forms contained an error: the title of the thesis referred to 'siblings of children *and young people* with complex medical needs', rather than just to 'children with complex medical needs' as set out in the original Application for Ethical Approval. It was therefore necessary to complete a 'Change of Title Request Form' prior to submitting the final thesis (see Appendix G).

3.5.2 Sampling and participants

Samples in qualitative research are generally homogenous and purposive, that is, participants are selected based on specific characteristics or their belonging to a certain group, in order to provide their own account of the phenomenon being studied (Vasileiou et al., 2018).

Sample size is generally smaller in qualitative than in quantitative research, and the number of participants required to answer the research question(s) usually becomes apparent through the course of the study (Marshall, 1996). Smith et al. (2012) suggest between 4 and 10 participants, and caution against having a sample that is too large to fulfil the requirements.

All participants in the current study met the inclusion criteria (see Table 3.1).

Table 3.1

Inclusion criteria for participants in the current study

Inclusion criteria	Rationale
Aged between 10 and 19 years old	To ensure participants have a certain level of language, maturity and experience to be able to engage in interviews.
Has a brother or sister (including full, half-, step-, adopted, fostered or deceased siblings) with CMN	To allow well siblings to participate regardless of biological connection.
Well sibling and sibling with CMN live together at least 50% of the time	To ensure greater homogeneity of experience for IPA. Participants will have experienced living with a sibling with CMN and the impact this has on day-to-day life.
Speaks English	To allow participants to understand the information sheet, provide assent/consent and engage in the interview.

Attends/attended an educational setting full- or part-time in the United Kingdom	Ensuring greater homogeneity of experience for IPA. Participants will be able to speak about the experience of attending an educational setting.
Has some understanding of their sibling’s complex medical needs	To enable participants to understand the aims of the study and provide informed assent/consent.

Note: Due to difficulties encountered during the recruitment process, the age range was changed from 11-18 to 10-19 years to expand the pool of potential participants.

3.5.3 Recruitment of participants

Recruitment commenced in April 2022 when an advert for the study (see Appendix I) was shared with The Maypole Project, a charity serving children with CMN and their families. The charity sent the advert to all families in its database, with details of the study and how to contact the researcher. No potential participants came forward at this stage of recruitment. Following discussions with staff at the charity, it was decided that an employee of The Maypole Project would speak directly to families with a child who was believed to be eligible to participate in the study. If families agreed to be contacted, the member of staff gave the parent’s e-mail address to the researcher, and she contacted parents directly with further information about the study. The researcher then arranged a phone call with the parents to explain the study in more detail, allow them to ask any questions and to check eligibility of the sibling (i.e. by checking they met the inclusion criteria).

In total, five parents of potential participants agreed to be contacted about the study. One conversation revealed that their child was not eligible due to the sibling having a diagnosis of autism spectrum disorder (ASD), which alone did not satisfy the criteria for CMN. A second parent did not respond to e-mails requesting a phone number to discuss the study and the child’s eligibility. In total, three interviews with potential participants were arranged to take place in October and November 2022.

Due to unforeseen circumstances, these interviews had to be postponed and parents were notified that the researcher would be in contact later in 2023 to rearrange them. However, none of the parents responded when contact was made in October 2023, so these interviews did not go ahead.

The charity was approached again in October 2023 to find out whether there were any new families who may have a child eligible for the study. However, no potential participants were forthcoming. Therefore, an amendment was made to the Application for Ethics Approval to enable participants to be recruited via social media (see Appendix J). Once approved, the participant advert was posted on Twitter and on relevant groups on Facebook for parents of children with complex medical needs. Interested parents were asked to send a direct (private) message to the researcher with their e-mail address. The eligibility and willingness of potential participants to be interviewed was checked via e-mail. This led to the recruitment of six participants, all aged between 11 and 15 years old.

Prior to the interviews, an information sheet for parents (see Appendix K) and one for participants (see Appendix L) were shared. Parents were also asked to complete an online version of the consent form (Appendix M) and participants an assent form (Appendix N).

3.6 Data collection

In this section, the methods used to elicit views of siblings of children with CMN are discussed, including semi-structured interviews and the interview design and process.

3.6.1 Semi-structured interviews

Semi-structured interviews have been lauded for their flexibility and versatility (Kallio et al., 2016). In particular, they allow the researcher to ask follow-up questions as they emerge during the interview process, and give space to participants to express their individuality (Kallio et al., 2016). Moreover, this style of interviews enables the researcher to deviate from the script and probe further on issues arising during the interview that had not been anticipated (Adams, 2015).

During the semi-structured interviews, an interview schedule was loosely followed (see Appendix O) to help ensure that all of the areas of interest for the study were covered, but with flexibility to ask follow-up questions where appropriate. The interview schedule was drafted following the literature review, based on the gaps in the literature identified and the research aims. Using the research questions as a starting point, the interview schedule was developed. The researcher met with her Director of Studies to review this and following feedback, additional questions were formulated, for example, to help differentiate between participants' primary and secondary school experiences.

It was important to pay extremely close attention to the participants and bracket off any preconceived ideas the researcher had about the topic in order to focus on and delve deep into each participant's unique understanding of their experiences (J. Smith et al., 2012). In this way, each participant was treated as an "experiential expert on the topic" (J. Smith et al., 2012, p. 64) and given the space and time to share their expertise in the semi-structured interview.

3.6.2 Interview design and process

For the study, the researcher met once with each participant for between 30 and 45 minutes online using Microsoft Team. Participants were given the choice between meeting in person and online, and all chose to meet online. Prior to commencing the interview, the researcher checked that participants had read the information sheet and asked whether they had any questions. Participants were given the choice of having a familiar adult accompany them, on the understanding that only the child/young person was able to answer the questions during the interview. One participant chose to have her mother in the room and five participants chose to be on their own.

Building rapport with participants is essential to ensure they are relaxed and feel comfortable enough to share their thoughts, feelings and experiences (Hannabuss, 1996). For this reason, the researcher began by introducing herself, reiterating the purpose of the interview and framing it as an informal chat. Participants were told there were no right or wrong answers to help put them at ease (J. Smith et al., 2012).

During the interviews, it was important to probe participants to reflect on their experience more deeply at times, using questions and prompts to encourage them to thicken their descriptions (Hannabuss, 1996). It was key to ask questions at the appropriate point in the conversation and to avoid interrupting, while ensuring the interview stayed on track and was completed within the time allowed (Hannabuss, 1996).

Towards the end of the interviews, participants were asked whether there was anything further they wished to share or if they had any questions. Participants were signposted to various organisations, such as The Maypole Project and Sibs, if they felt they needed further support with the topics explored during the interview.

The semi-structured interviews were recorded using a digital voice recorder, with consent from participants and their parents. The recordings were then transferred securely to the researcher's university OneDrive for Business account and transcribed manually. Following transcription, the recordings were deleted from the digital recorder and from the researcher's OneDrive account. The transcripts were password protected and saved with a generic file name that did not include any participant details, on a password protected laptop.

3.7 Data transcription and analysis

In this section, the data transcription and analysis processes are described, including the six stages involved in IPA, as set out by Smith et al. (2012).

3.7.1 Transcribing the data

The decision was made to transcribe the data manually, that is, without the aid of transcription software, in order to help the researcher familiarise herself with the data. Furthermore, it was felt that transcription software may not be able to pick up the emotional aspects of the interviews, e.g. pauses and sighs, which can affect the delivery of the interview content (Halcomb & Davidson, 2006). Nevertheless, it was deemed unnecessary to transcribe information which would not be analysed (J. Smith et al., 2012). Although transcription is a time-consuming process (Halcomb & Davidson, 2006), when weighed against the potential benefits, it was deemed a worthwhile endeavour.

3.7.2 Analysing the data

Smith et al. (2012) state that there is no single right way of conducting analysis in IPA research but provide a heuristic framework for analysis for inexperienced researchers, which in this instance, was followed. The following section outlines the six stages of this framework.

It should be noted that the current study employs the terminology set out by Smith et al. (2012) including ‘emergent’, ‘subordinate’, ‘superordinate’ and ‘master’ themes. Nevertheless, it is acknowledged that new terminology, such as ‘personal experiential statements’ and ‘group experiential statements’ has been suggested to replace these (J. A. Smith & Nizza, 2022).

3.7.2.1 Stage 1: Reading and re-reading. Smith et al (2012) advise listening to the recording of the interview while reading the transcript for the first time, to help embed the participant’s voice in the researcher’s mind. Therefore, the researcher read and re-read the transcript of each interview, holding the participant’s voice in mind each time. The researcher re-listened to the recordings at times to remind herself of the participants’ tone at certain points, but having transcribed the interviews manually, she was quite familiar with their voices. During this phase, the researcher made a note of her initial reactions and most prominent thoughts following the interviews, to help bracket these off.

3.7.2.2 Stage 2: Initial noting. During this stage in the process, the researcher made notes on anything of interest as she read through the transcripts one by one. She noted descriptive comments, such as noting what mattered to participants, as well as more interpretative comments, where she examined how and why siblings had the concerns they expressed (J. Smith et al., 2012). Comments were noted in a table and font styles were used to distinguish between descriptive (plain text), linguistic (italics) and conceptual comments (underlined) (see Appendix P).

3.7.2.3 Stage 3: Developing emergent themes. This stage of the process involves a delicate balance between reducing the volume of data (the transcript and initial notes) and maintaining the complexity of it (J. Smith et al., 2012). It was primarily the notes on the transcript that were used to develop emergent themes, retaining the interpretative aspect of IPA.

3.7.2.4 Stage 4: Clustering emergent themes. The next stage involves looking for connections across emergent themes within a single transcript, and developing subordinate themes under which the emergent themes fit. Smith et al. (2012) assert that not all emergent themes need be used at this stage and this will depend primarily on the research question and the scope of the research. Once emergent themes were grouped according to the most logical connections between them, titles for the subordinate themes were chosen in a process known as abstraction (see Appendix Q) (J. Smith et al., 2012).

3.7.2.5 Stage 5: Moving to the next case. It is important to treat each case individually when conducting IPA research (J. Smith et al., 2012). Therefore, it is necessary to bracket off the findings from previous cases when carrying out stages one to four for each new case (J. Smith et al., 2012). The research journal was used to help with this process to ensure the researcher was able to approach each participant's transcript afresh, allowing new themes to emerge with minimal interference from previous transcripts.

3.7.2.6 Stage 6: Looking for patterns across cases. The final stage of IPA consists of looking for patterns across cases (J. Smith et al., 2012). This was achieved by writing each subordinate theme from all of the cases in separate cells on a spreadsheet, looking for connections or similarities between themes, and grouping them together. The results are presented in a table showing how superordinate themes relate to one another under master themes (see Appendix R) (J. Smith et al., 2012).

3.8 Ethical considerations

As well as obtaining approval from the School of Psychology at the University of East London, this research was conducted following the BPS's Code of Human Research Ethics, which prioritises respect for the rights and dignity of participants (Oates et al., 2021).

3.8.1 Informed consent

Informed parental consent was sought for all participants, as well as informed assent of the participants who were all below the age of 16.

From the outset, participants and their parents were informed of their right to withdraw from the research at any stage of the process. Participants were informed that they could withdraw consent for their anonymised data to be used up to two weeks after the date of the interview, at which point data analysis would have commenced. None of the participants who signed the consent/assent forms chose to withdraw at any stage.

3.8.2 Confidentiality and anonymity

All data was anonymised at the point of collection. Participants were given the opportunity to select their own pseudonym for the study, and one for their sibling, as well as any other people mentioned during the interview. Some participants requested that the researcher chose pseudonyms for them. During the transcription process, only pseudonyms were used.

Once transcription had been completed, voice recordings of the interviews were deleted. The transcription of participants' anonymised responses was stored securely on the researcher's university OneDrive for Business account. No information which could potentially identify participants was stored alongside the data.

Participants were informed at the start of the interview that if there were any concerns that the participant or others may be at risk, confidentiality may need to be broken to help keep them and others safe. Otherwise, all information shared would remain anonymous, and steps would be taken to protect their privacy and that of other family members.

3.8.3 Care of participants

As previously outlined, it was important to build rapport with participants at the start of the interviews to ensure they were comfortable responding to the interview questions. Nevertheless, there remained a risk that talking about their experiences may be upsetting for some participants. Participants were offered to pause or stop the interview if they showed signs of distress. Additionally, as part of the debriefing process, participants and their parents were provided with a list of organisations which provide counselling and support that they could access.

3.8.4 Participant characteristics

Information about each of the participants is set out below, including participants' age and that of their sibling with CMN, gender and that of their sibling, and the age gap between them (see Table 3.2). Two of the participants were sisters* (Daisy and Ella), only one was male (Zack) and all but one of the siblings with CMN were female (Knox, Mallory's brother, is the exception). All participants were older than their sibling with CMN, and the gap in age ranged from 2 to 10 years (mean = 6.33 years). Participants were aged between 11 and 15 years old (mean = 13.17 years) and siblings with CMN were aged 2 to 13 (mean = 6.83 years).

Table 3.2

Information about participants and their siblings with CMN

Pseudonym of participant	Age	Gender	Pseudonym of sibling with CMN	Age of sibling	Gender of sibling	Age gap in years
Paige	12	Female	Moo	2	Female	10
Daisy*	14	Female	Starla	5	Female	9
Ella*	11	Female	Starla	5	Female	6
Mallory	15	Female	Knox	6	Male	9
Anna	12	Female	Sarah	10	Female	2
Zack	15	Male	Lisa	13	Female	2

Although the information was not systematically collected, participants spoke of having between one and four siblings, although each had just one sibling with CMN. Participants were not asked to disclose demographic information such as ethnicity, religion or country of origin, though all participants appeared to be white and fluent speakers of English. Participants hailed from different parts of England and seemed to represent a relatively broad spectrum of socio-economic backgrounds.

Siblings' conditions included Down's syndrome, Rett syndrome (a genetic neurological and developmental disorder), XYY syndrome (a rare chromosomal disorder) and Crohn's disease requiring chemotherapy treatment leading to severe immunosuppression, alongside other learning difficulties including ASD and ADHD. During the interviews, some of the participants disclosed information about their own confirmed or suspected health or learning needs, including a heart condition, epilepsy, ASD and ADHD. In tables and following quotes, a coloured label is used to help the reader distinguish between participants.

3.9 Chapter summary

This chapter set out the interpretive paradigm underlying the current study. It followed that the research took a subjectivist epistemological position and a critical realist ontological position. IPA was chosen to analyse the data, and its philosophical underpinnings were explored. Next, the research design, recruitment and data collection methods were presented, followed by the ethical considerations for the current study into the lived experiences of siblings of children with CMN. Finally, the characteristics of participants were presented, in preparation for the analysis of interview findings. The chapter which follows presents the findings of the current research into the lived experiences of siblings of children with CMN using IPA to analyse participants' responses.

Chapter 4: Findings

4.1 Chapter outline

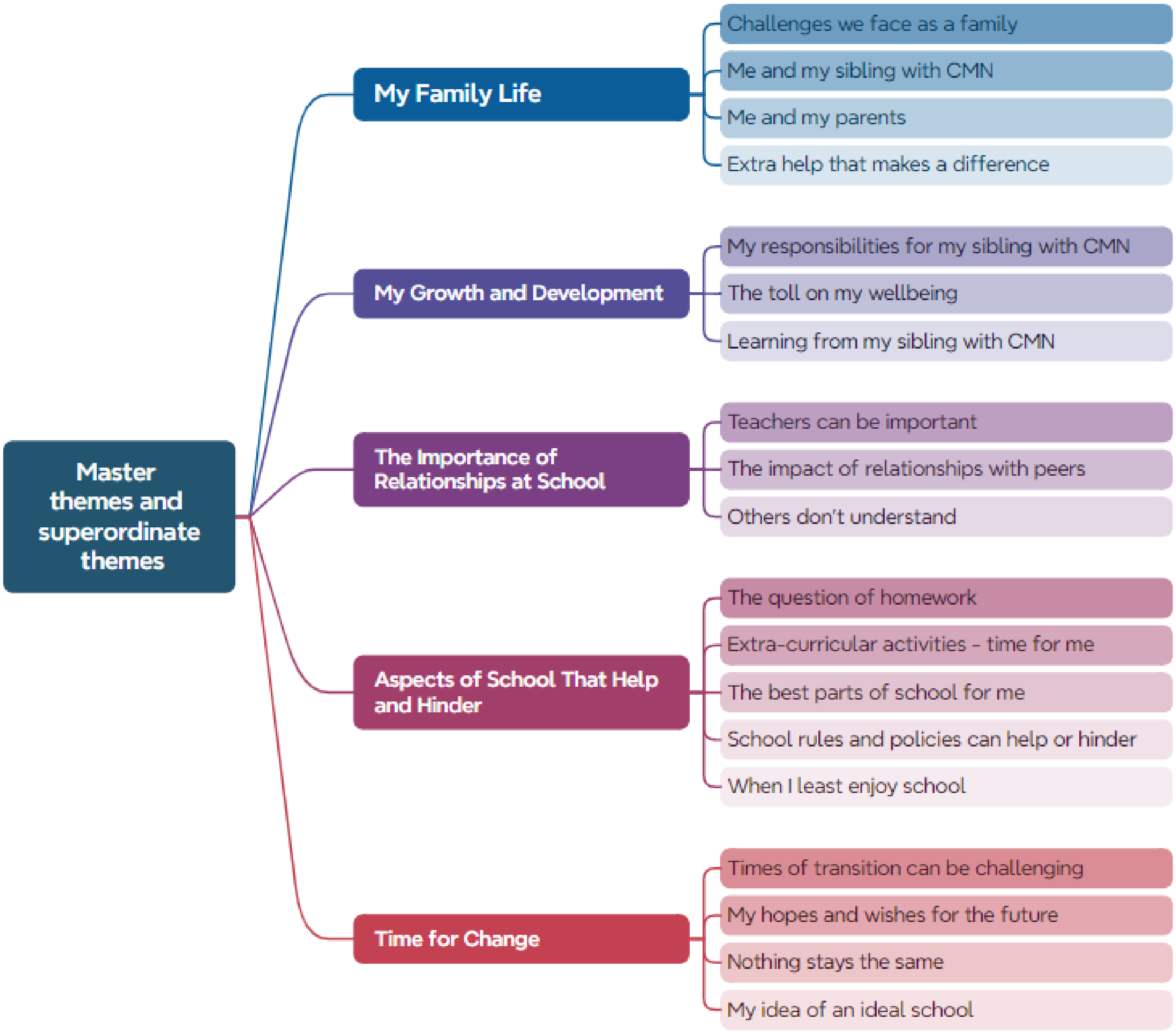
The previous chapter outlined the researcher's position, the research design, data collection methods and ethical considerations employed in exploring the lived experiences of siblings of children with CMN. The current chapter presents the findings from semi-structured interviews with six siblings of children with CMN, including the five master and related superordinate themes derived from the data. These themes are explored in detail with supporting evidence from each participant's interview using an interpretative phenomenological analytical approach.

4.2 Master themes and superordinate themes

Five master themes were identified from the data through the analytical process , each with three to five superordinate themes, as set out in Figure 4.1. All participants mentioned each master theme at some point in their interview, though not every superordinate theme was discussed by every participant, highlighting both the convergence of their narratives and their unique, individual experiences.

Figure 4.1

Master and superordinate themes derived from the data



4.3 Master theme 1: My Family Life

The master theme, ‘My Family Life’, comprises four superordinate themes: ‘Challenges we face as a family’; ‘Me and my sibling with CMN’; ‘Me and my parents’; and ‘Extra help that makes a difference’, as shown in Figure 4.2. Table 4.1 shows which participants informed each of the superordinate themes. All participants reported positive experiences of family life, with some acknowledging the challenges of having a sibling with CMN, either as a direct result of the sibling's behaviour or indirect implications of having a sibling with CMN.

Figure 4.2

Superordinate themes linked to 'My Family Life'

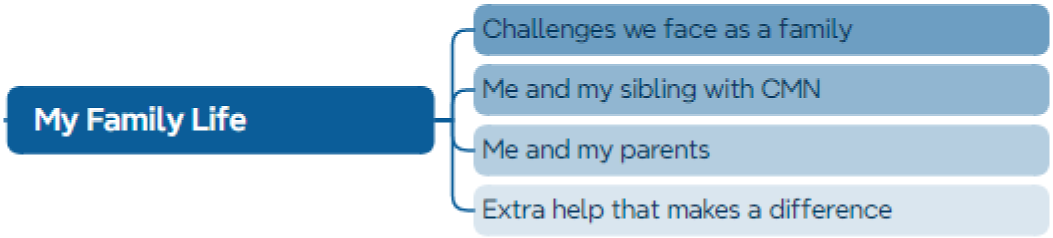


Table 4.1

Participants who spoke about 'My Family Life'

	Paige	Daisy	Ella	Mallory	Anna	Zack
Challenges we face as a family	✓			✓	✓	
Me and my sibling with CMN	✓	✓	✓	✓	✓	✓
Me and my parents	✓	✓	✓	✓	✓	✓
Extra help that makes a difference		✓	✓	✓	✓	

4.3.1 Superordinate theme 1.1: Challenges we face as a family

Mallory speaks extensively about her brother's difficulties resulting from his CMN, including his physical difficulties, his aggression towards her and his powerlessness to control his behaviour: “He’s violent, really violent, especially towards me and my mum. Erm, he swears a lot, he shouts, he throws things, yeah, he’s, he can be really aggressive,” (Mallory, lines 10-11). The repetition in the phrase, “violent, really violent”, the use of the rule of three to illustrate her brother’s behaviour and the omission of the word ‘and’ in “he swears a lot, he shouts, he throws things” highlights the intensity of the challenges her brother experiences as well as its impact on Mallory and her mother. Mallory also describes the lack of control her brother has over his behaviour: “it seems quite nasty, but you put everything down to it, do you know what I mean? So, you can’t really, you’re not allowed to tell him off because he can’t help it,” (Mallory, lines 37-38). Mallory seems to feel guilty for attributing her brother’s behaviour to his CMN, labelling it as “quite nasty” to do so. Furthermore, Mallory checks to ensure the interviewer understands where she is coming from, “do you know what I mean?”, as if seeking reassurance or confirmation that she is not viewed as “nasty”. Mallory seems hesitant about how to convey her brother’s difficulties, correcting herself when she begins, “you can’t really, you’re not allowed to […]”, which may reflect her distrust of or unease around adults who, with the exception of her mother, she feels have lacked understanding and empathy.

Anna describes the difficulties that her sister encountered at school as a result of her CMN: “[…] my sister wouldn’t get treated that well because she was a bit different and had learning disabilities, um, but that was only, like, once in a while” (Anna, lines 103-104). In contrast to Mallory, Anna seems to want to minimise the impact of her sister’s CMN through the phrases, “[not] that well”, “a bit” and “only”, or at least convey the infrequency of her ill treatment at school. However, Anna’s sister eventually moved school when Anna went to secondary school, implying that the difficulties her sister faced were greater than, perhaps, even she realised: “when I left the school, Sarah didn’t really feel, um, in place without me, so then, that’s when she moved to W School, that’s when she moved to another school,” (Anna, lines 61-62). Similarly, the phrase “Sarah didn’t really feel, um, in place without me” seems to play down the difficulties that her sister experienced. Her hesitance conveys her reticence in describing how her sister felt once she had left the school, which could signify a whole host of thoughts and emotions: anger, sorrow, guilt, confusion, embarrassment, relief, etc. Overall, there is a sense that Anna, like Mallory, wishes to protect her sibling from the judgement of others and from the challenges faced because of her underlying CMN.

Paige describes the symptoms her sister experiences as a result of her CMN, and the resulting challenges these pose for her:

> Um, it’s quite, it’s quite hard to be honest in the mornings ‘cause when you’re trying to get her dressed, she’s like, quite floppy. I mean, she also has seizures, yeah, and it’s quite hard to, like, I mean, I’m not sure how to explain it, but I think it’s like absence seizures, but she’ll just space off, like she’ll just space out basically. (Paige, lines 13-16)

Paige conveys that not only is it physically difficult to dress her sister, but that doing so takes its toll on an emotional level. She repeats “it’s quite hard to”, cutting herself short the second time, so it is unclear whether she was referring to the difficulty in explaining her sister’s presentation as a result of her CMN (as she mentions), or if she was initially going to describe another challenge that she faces, before going on to describe her sister’s absence seizures. Either way, Paige’s discourse conveys a chain of difficulties resulting from her sibling’s CMN, which include practical and emotional challenges as well as the struggle to convey these through language.

4.3.2 Superordinate theme 1.2: Me and my sibling with CMN.

Zack describes a loving relationship with his sister, despite his sister's difficulty in expressing her love for him:

> […] we get on quite well, she, she, like, loves me a lot, but in ways, she just, like, doesn't understand how to express it and she just, yeah, it can be a bit confusing for her, but we all know, like, down below, that she's very nice and loving. (Zack, lines 2-4)

Zack hints that his sister's words and actions do not always convey a loving relationship. Nevertheless, he knows that, deep down, she does love him. He shows empathy for his sister in explaining the difficulties she has, "she, just, like, doesn't understand" and "it can be a bit confusing for her", rather than expressing any sort of anger or frustration towards his sister or at his own predicament.

Anna balances the positive aspects of her sister against the negatives: "Um, although she can be a bit difficult sometimes, like normal siblings, um, she's always fun to be around," (Anna, lines 2-4). Anna comments that her sister "can be a bit difficult sometimes", then acknowledges that this can apply to any sibling, not just one with CMN. She concludes: "I wouldn't really want a different family because we have chaos with my sister, although she brings, like, life, happiness and joy to our family as well," (Anna, lines 30-31). Again, Anna pits the good, the "life, happiness and joy" her sister brings, against the bad, the "chaos", and decides that she is happy with the family she has.

It is notable that Zack and Anna are both two years older than their sibling with CMN, and this proximity in age may play a role in their closeness as siblings compared to some of the other participants, whose gap of up to 10 years in age seems to correlate with a greater sense of responsibility and caring duties towards their sibling with CMN.

Ella interprets her own similarity to her sister as indicative of their close relationship:

> I feel like we're quite close because, erm, she's quite like, she needs, like, something to sleep, she needs like a little teddy, and I sometimes, I really can't sleep unless I have a little blanket or something, so that's kind of close and similar, I feel. (Ella, lines 3-6)

Ella starts and ends this sentence with the same phrase, "I feel," emphasizing her own perspective, with which others may not agree, as well as conveying her tentativeness. She initially describes feeling like "*we're* quite close" and ends the sentence by saying, "*that's* kind of close and similar", acknowledging that her description of their proximity is more in a physical sense than a relational one. At 11 years old, Ella is the youngest participant, and this is apparent in her description of her closeness to sister with CMN.

Mallory, who is nine years older than her brother, describes the difficulty she has in taking him out the house:

> I take him out a lot, like, well, I try to take him on walks and stuff, but it never really ends well. Erm, and, yeah, I do look after him in the house and I'll, like, have little movie nights with him and stuff but, yeah. (Mallory, lines 82-84)

It appears that Mallory is frustrated by the discord between the relationship she imagines having with her brother and the one she does have. Mallory initially states that she takes her brother out "a lot" and then corrects herself and clarifies that she *tries* to take him out, "but it never really ends well". There is a sense of wistfulness when she says, "I'll, like, have little move nights with him and stuff, but yeah," the word 'but' implying that the relationship she has with her brother is not everything she wishes it could be.

While Mallory is disappointed with certain aspects of her relationship with her brother, Daisy is surprised and delighted by aspects of her relationship with her sister. Daisy recalls her sister being excited to see her after a brief period away from the house:

> The minute she saw me coming down the stairs she suddenly started, like, being like really happy and she was, like, shaking and stuff, like she does when she's really excited and I was like, oh my gosh, she remem…, she actually remembers me, she's happy to see me, I was really happy, I really liked that, it was nice. (Daisy, lines 29-33)

Daisy stops herself mid-word, "she remem…, she actually remembers me", conveying her disbelief that her sister reacted to seeing her in this way, as if reliving the moment as she is recounting it. Daisy expresses her delight at this revelation, and there is a sense of relief that comes through as her phrases grow increasingly shorter and she seems to settle in to this new knowledge about her sister's capabilities which were not previously evident.

While each of the participants' descriptions of their relationship is different, their descriptions are all permeated by a deep sense of love and protection; for the most part, participants tried to show their sibling with CMN in the best possible light and to convey their closeness to them.

4.3.3 Superordinate theme 1.3: Me and my parents

All participants describe positive relationships with their parents, with some feeling closer to one parent than the other, and some lamenting the lack of time spent together. Mallory describes her mum as her "best friend" (Mallory, line 59), in part because her mum had her when she was very young, but also because her mum is the only one who really understands her, "my mum [understands], really. I think that's literally it," (Mallory, line 205). At one point, Mallory accidentally refers to "his [her brother's] mum" (Mallory, line 76), before correcting herself, "well, our mum" (Mallory, line 76), highlighting the extent to which she seems to have internalised the notion that her mother is a friend. Nevertheless, there are times when she positions her mother in more of a parental role, for instance, when she has been up late because her brother has had seizures and her mum allows her to sleep in: "when I've finally got to sleep my mum hasn't been able to wake me up and my alarms haven't woken me up, and she's realised that I, like, need the sleep," (Mallory, lines 145-146), and in relation to school, "I've absolutely begged my mum to take me out of it 'cause it's just awful," (Mallory, lines 128-129). Despite their closeness, Mallory feels she does not have enough time with her mum: "I do love my mum, but I wish I could spend more time with her," (Mallory, line 61).

Paige describes enjoying time spent with her mum: "I think the funnest [sic] thing that me and my mum do is we like to go out to places sometimes. Like, to go eat. Or like, just like, to talk for a long drive," (Paige, lines 73-74). The simplicity of the activities that Paige and her mum do together conveys the closeness between them; they do not need anything fancy or complicated to have fun. In contrast, she does not spend a lot of time with her dad, despite their apparent similarity:

> With my dad, well, yeah, with my dad, I don't really do a lot with him. But we're more of like a, like a, like kind of, I don't know how to put it, we're like two peas in a pod but we don't really, like, hang out with each other. (Paige, lines 76-78)

Paige's use of the simile "like two peas in a pod" to convey how similar she is to her dad in fact creates a sense of distance between them – rather than a simple description of what they have in common, the use of a linguistic trope seems to act as a barrier to knowing anything about her father, reinforced by the fact that they do not spend much time together.

Conversely, Daisy describes a closeness to her father which she does not share with her mother:

> My dad, we joke around a lot. We have, erm, we have similar music tastes so we share music together. Erm, I can't, I don't know what to say about my mum and I, because she does the school runs and stuff, but I feel like I don't get to see her that often and I don't get to spend time with her often. (Daisy, lines 40-43)

> I can’t really put my finger on it but I guess I’m kind of more my dad’s girl than my mum’s girl, so I used to prefer spending time with my dad a lot more than my mum which is kind of a bit unfair I guess, but like, he’d always take me on days out and mum would always be at home with my siblings and stuff. (Daisy, lines 48-51)

Daisy struggles to articulate why she is closer to her dad than her mum, saying “I don’t know what to say about my mum and I” and “I can’t really put my finger on it,” but she seems to relate it to being “kind of more my dad’s girl” and the fact that her mum “would always be at home with my siblings”. Daisy seems to feel guilty for having a preference for spending time with her dad, “[it’s] kind of a bit unfair I guess,” but recognises that it is most likely the circumstances rather than choice that has led to this. Furthermore, she goes on to explain that her mum works night shifts during the week and day shifts at the weekend, which also limits the time they spend together, and expresses a wish to spend more time with her mum going forward, “I think it would be nice to swap that around every once in a while in the future,” (Daisy, lines 51-52).

In contrast, Ella feels close to both parents, particularly her mother:

> They’re very nice and I really think we’re quite close. I look a lot like my mum. Everyone says so. And I really like dancing in the kitchen and stuff with my dad. And mum’s really good with, like, as I’m getting older and stuff, that kind of stuff, so, and they do help a lot, say I’m stuck on something, they will help me, so, pretty good. (Ella, lines 33-36)

Ella equates looking like her mother to a sign of the close bond they share. She particularly appreciates her mum’s support as she grows up and experiences new challenges for the first time. Noticeably, she switches from talking about her parents individually to talking about them together, highlighting the equal weight each of them has in her life.

For Zack, his parents' attendance at his football matches is a sign of their love and support for him, and he particularly appreciates that they are both able to be there: "[…] with sporting activities as well, like, I play football myself, and they, they'd always come down and support, and both of them would, which is quite nice," (Zack, lines 26-28). He also talks about his parents understanding what he goes through: "My, my relationship with my parents is very good. They, they understand, like, what, what goes on, and stuff like that. They, they're like very helpful, they're kind, yeah, and they stick up and they help with anything," (Zack, lines 17-19). Zack's repetition of "my", "they" and "what" conveys the depth of thought as he tries to relay what his relationship with his parents is like. He is keen to emphasise how important they are to him, adding further information, "and they stick up and they help […]", to demonstrate this.

4.3.4 Superordinate theme 1.4: Extra help that makes a difference

Several participants spoke of the additional support their sibling receives in the home or at school, as a result of their CMN. At times, this support has a knock-on effect in providing the family with respite.

Daisy and Ella's sister with CMN, Starla, has a carer who visits twice a week: "if Starla's carer is here, then Starla's carer will be here looking after her. And then, otherwise, if my mum was working night shifts, I'll be downstairs feeding my sister, getting her changed, ready for bed," (Daisy, lines 71-74). Starla's carer appears to provide a break for Daisy from caring responsibilities, particularly when her mother is working. Her sister, Ella, refers to the respite Starla's carer provides for her parents in particular, as well as for the family as a whole:

> On Thursdays and Tuesdays erm, I think, my parents can relax more as well because Starla has her… a carer round to help, so that helps as well, ‘cause it gives us a break and Starla gets, Starla really likes Hannah [her carer] as well, so, yeah. (Ella, lines 58-60)

Ella mentions that Starla “really likes” her carer, indicating the benefits for Starla of having a carer who is external to the family.

No other participants mention their sibling with CMN having a carer at home. Nevertheless, other people can provide support to the family. For example, Mallory enjoys going to her mum’s boyfriend’s home as the additional adult provides some support to her and her mum:

> We go to mum’s boyfriend’s on the weekend and that’s always good […] because there’s another adult there, erm, and that’s where we’re going to be moving in soon so it’s nice to see it all like getting better and going out more and stuff. (Mallory, lines 18-21)

There is a sense of optimism and positivity in Mallory’s discourse; a suggestion that life with her brother is not, and in the future may not always be, so difficult.

As well as support at home, siblings with CMN may be supported at school. Anna explains that her sister received help in her first school: “Um, when my sister started at the school, she had a one-to-one to help her a bit if she found it tricky,” (Anna, lines 55-56). Her sister receiving support at school seems to provide reassurance to Anna that she is being well cared for. She describes that in response to her sister being left out by her classmates, the teachers would:

> [….] ask if she was okay and if she wanted to join, um, me or a couple of other kids, um, in school and then I would, um, they did a lot about it, they, they helped a lot with Sarah, which was really nice. (Anna, lines 111-113)

Anna is complimentary of the teachers at her sister's school, while appearing to brush off her own role in helping her sister; when talking about what she would do, she leaves the phrase unfinished, and instead returns to praising the help from teachers. This encapsulates the participants' humility in sharing their own role in supporting their siblings with CMN and their gratitude for any additional support from beyond the immediate family.

4.3.5 Summary of 'My Family Life'

The master theme, 'My Family Life', encompassed participants' views and experiences relating to the specific challenges they encountered as a result of sibling with CMN, as well as details of their relationship with their sibling and parents, and external sources of support. The challenges encountered were behavioural, practical and emotional in nature; their relationship with their ill sibling was close and loving, albeit not devoid of difficulties, and the reality of their relationship was not always what they imagined or hoped. The bond between well siblings and their parents was strong and parents were often the only people who understood their experiences, although they were sometimes closer to one parent than the other. Additional support for their sibling, when present, provided a break from caring responsibilities and respite for the whole family.

4.4 Master theme 2: My Growth and Development

Three superordinate themes comprise the master theme, 'My Growth and Development'. They are: 'Responsibilities related to my sibling with CMN', 'The toll on my wellbeing', and 'Learning from my sibling with CMN', as can be seen in Figure 4.3. The participants whose accounts informed each of the superordinate themes are displayed in Table

4.2. ‘My Growth and Development’ entails both the challenges that participants face as a result of having a sibling with CMN, and the benefits it proffers.

Figure 4.3

Superordinate themes linked to ‘My Growth and Development’

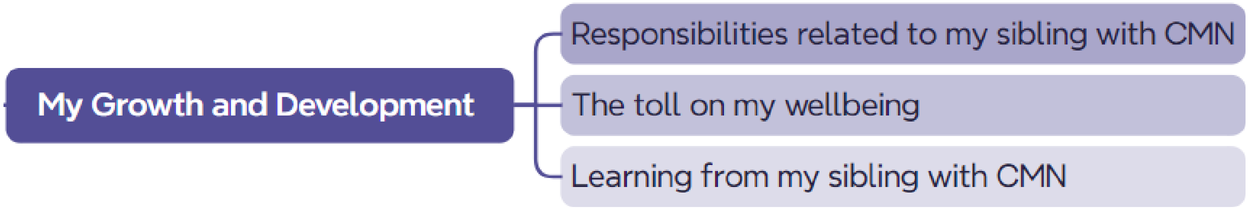


Table 4.2
Participants who spoke ‘My Growth and Development’

	Paige	Daisy	Ella	Mallory	Anna	Zack
Responsibilities related to my sibling with CMN	✓	✓	✓	✓		
The toll on my wellbeing	✓	✓	✓	✓		✓
Learning from my sibling with CMN	✓		✓		✓	

4.4.1 Superordinate theme 2.1: Responsibilities related to my sibling with CMN

Four participants mention responsibilities they have related to having a sibling with CMN. In describing her morning routine, Paige explains:

> I get Moo dressed when she’s having, like, good days. Erm, I mainly always get Frankie [another sibling] dressed. Erm, but I think it was this morning that I got Moo dressed and she was really, really floppy, and it was really sad to see that, but, erm, I had to just change her into an outfit and do her, do her nappy, and then I did Frankie as well […]. (Paige, lines 85-88).

Paige states that she only dresses Moo, her sister with CMN, on “good days”, yet describes having dressed her this morning when she was “really, really floppy”, presumably not a “good day”, but perhaps not as bad as some. This undoubtedly affects Paige emotionally, “it was really sad to see that”, but she shows resilience and determination to complete the task, as well as seeing to her other sibling afterwards. From this we can infer that she puts her responsibilities towards her sibling with CMN above her own needs.

Daisy describes how looking after her sister makes her feel more like a carer than a sister:

> Sometimes I kind of feel like a carer to her more than her sister, like, I have to feed her a lot and I also have to, like, change her and stuff, which I guess is expected as a sibling but then I also feel like an additional carer sometimes when my parents go out, when I have to look after her for, like, an hour or so. (Daisy, lines 3-6)

Daisy suggests that some of the responsibilities she has can be “expected as a sibling”, but this does not detract from her feeling “like a carer” at times. Daisy appears to attempt to soften the statement, using modifiers like “sometimes” and “kind of”, conveying a sense of guilt or discomfort in sharing how she feels.

Mallory talks about the pressure she feels to behave like an adult around her brother with CMN:

> It puts a lot of pressure on really, because obviously, I’m just his sister, I’m not really an adult, so I have to, like, not say ‘no, Knox, you can’t do that’ or, like, retaliate. It does take a lot because, obviously, he’s saying all these things and doing all these things. (Mallory, lines 40-42)

Mallory evokes how she imagines most sibling relationships play out; one sibling provokes the other and the other fights back. However, as the sibling of a child with CMN, Mallory must act in a more mature and responsible manner, which “puts a lot of pressure on”. Mallory conveys her frustration at this situation by asserting that she is "just his sister" and "not really an adult", even though, it is implied, she is obliged to act like the latter.

Ella feels an increased sense of responsibility to look out for others stemming from taking care of her sister with CMN:

> I feel like I have a bigger sense of, like, responsibility at school, like, trying to make sure I do … like, get everything is… like, safe… not safe, not safe, everything is, like, correct, like, as though, with Starla's it's similar because I have to make sure […] if she was to fall back she wouldn't hit her head or anything so I have to make sure everything's safe around her […] (Ella, lines 182-186)

Ella initially states that she has to ensure that everything is "safe", then corrects herself, repeating "not safe, not safe" and affirms that what she means is "correct". Nevertheless, when describing a similar situation with her sister with CMN, she again employs the word "safe", implying that this may have been the word she had intended after all. Ella seems to have internalised the need to keep her sister safe and applied this more widely in situations involving other people. By correcting her language, Ella implies that she knows this is not entirely necessary or appropriate in other settings such as school, but it is a responsibility she feels, nonetheless.

4.4.2 Superordinate theme 2.2: The toll on my wellbeing

Several participants speak about disrupted sleep due to having a sibling with CMN, which can also affect their ability to function the following day. Zack states, "she finds it, like, difficult to get out her feelings and sometimes she can just completely explode and just go on massive, like, meltdowns for hours at, like, nighttime and it can affect sleeping and stuff like that," (Zack, lines 105-107). The metaphor he uses, "she can just completely explode," conveys the uncontrollable, all-encompassing nature of his sister's "meltdowns". In comparison, his statement that “it can affect sleeping and stuff like that” seems to downplay the effect this has on him.

Mallory explains the effects of prolonged periods of disrupted sleep:

> I’m obviously tired a lot of the time, from waking up early and going to bed late. Erm, and then not sleeping much through the night. I wake up in the middle of the night now because my body’s trained to do it from when Knox had seizures every night. Erm, so yeah, it’s, I’m pretty much always tired. (Mallory, lines 209-212)

Even now that Knox’s medication is more effectively controlling his seizures, Mallory feels her body is “trained” to wake up in the middle of the night, implying the enduring, potentially traumatising, effect of his seizures on her. Similarly, Ella talks about being having been woken up by her sister in the past, with the effects still felt in the present:

> […] as me and Starla share a room, sometimes at night, say she cries, which she hasn’t done in a long time, but say she cries, as my bed’s higher up than hers, I have to get out of bed and that, to calm her down, so sometimes that can be, like, that could, if it’s like really late, and then I can’t go back to sleep easily, I can be really tired in the morning. But that doesn’t happen as often as it used to. (Ella, lines 253-256)

Although Ella states that this has not happened for a while, her use of the present tense and inclusion of details such as how her bed is positioned in relation to her sister’s gives the impression that disrupted sleep is an ongoing issue that continues to affect her, even if it is primarily the memory of it. Ella also clarifies that it “doesn’t happen as often as it used to,” implying it does still happen at times.

Paige speaks about the effect on her when her sister is unwell:

> […] it just upsets me that I know that Moo’s not having a good day and it’s just not going to be a good day for her and she’s like, it’s just quite like a hard day when you know that you’re sister’s like, not, I don’t know how to put it, but like, she’s not, I don’t know the word but she’s not… (Paige, lines 147-150)

At this point, Paige's mother, who was in the room, suggested the phrase she was looking for was "very well," with which Paige agreed. It is noteworthy that Paige struggled to articulate a seemingly simple phrase, and although these may not have been the exact words she had in mind, it suggests that Paige had difficulty accepting her sister's ill health and felt powerless to change it.

Daisy also talks about the effect of knowing her sister is in hospital:

> I mean, sometimes when she's in the hospital, I can get, I can get kind of worried, like is she gonna be okay and stuff, but I manage to kind of like put that aside and wait 'til later to kinda stress about that and focus on what I'm doing in the minute. (Daisy, lines 151-154)

Daisy says she is able to "put […] aside" her worry and focus on the present, implying she compartmentalises her concern for her sister while she needs to focus on other matters. Nevertheless, the worry seems to seep into her discourse as she talks about her sister being in hospital, using numerous fillers, such as "I mean," "like," and "kinda", indicating a sense of anxiety and unease. It is a reminder that while the worry of a sibling with CMN in hospital may be put to one side momentarily, it cannot be eliminated entirely.

4.4.3 Superordinate theme 2.3: Learning from my sibling with CMN

As well as the negative impact of having a sibling with CMN, participants speak with pride about what they have learnt from them. Anna, in particular, appreciates what her sister has taught her:

> I would say Sarah has, she's taught me a lot about patience because sometimes she doesn't really get the right answer so you would have to help her and have a lot of patience with her. She does understand though. (Anna, lines 168-170)

It is important to Anna to convey that her sister *can* understand what she is being taught, so long as the person teaching her has an adequate level of patience.

Ella has learnt to be particularly careful around her sister to keep her safe, and carries this with her outside of the home: "I'm used to being extra cautious at home, so then when it comes to school, it's like, it's something that I can't exactly just stop and then start, pick up again, so yeah," (Ella, lines 196-197). In a similar vein, having a sister with CMN has imbued Paige with a greater understanding of other people:

> I feel like I understand people more than, like, how other people do. I don't know how to put that, but I mean like, with Moo, I understand a lot, but she doesn't say anything, but I know what she wants when, like, she just looks at me. (Paige, lines 259-262)

Paige is skilled at understanding her sister's needs even though Moo is unable to speak, and this gives her confidence in her ability to understand others better than most people.

4.4.4 Summary of 'My Growth and Development'

Within the master theme, 'My Growth and Development', participants spoke about their responsibilities related to having a sibling with CMN, the impact on their wellbeing, and what they had learnt from their sibling. At times, participants put the needs of their sibling with CMN before their own, and felt more like a carer, or were forced to act more like an adult, than a sibling. Well siblings frequently experienced disrupted sleep, which could have enduring effects even once the disruptions had stopped. Siblings could be upset or worried knowing that their sibling was unwell but tried to compartmentalise these feelings. In addition to the more negative impact of having a sibling with CMN, well siblings acquired positive attributes such as patience and understanding.

4.5 Master theme 3: The Importance of Relationships at School

This master theme encompasses the role teachers play ('Teachers can be important'), the impact of friends and more negative interactions with peers ('The impact of relationships with peers’) and the feeling that people outside of the home do not understand the challenges faced by siblings of children with CMN (‘Others don’t understand’), as shown in Figure 4.4. Table 4.3 shows which participants informed each of the superordinate themes.

Figure 4.4

Superordinate themes linked to ‘The Importance of Relationships at School’

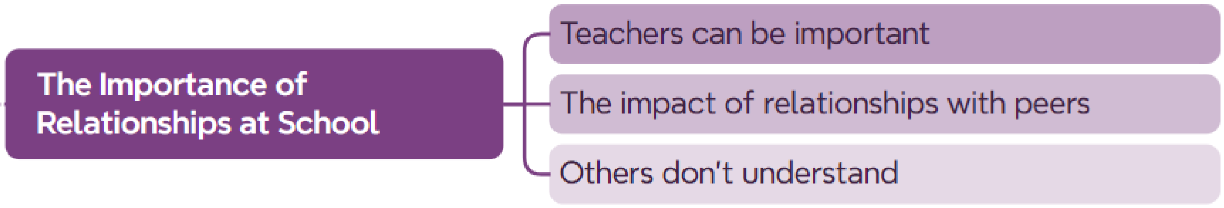


Table 4.3

Participants who spoke about ‘The Importance of Relationships at School’

	Paige	Daisy	Ella	Mallory	Anna	Zack
Teachers can be important	✓	✓	✓	✓	✓	✓
The impact of relationships with peers	✓	✓	✓	✓	✓	✓
Others don’t understand	✓			✓		✓

4.5.1 Superordinate theme 3.1: Teachers can be important

All participants emphasise the importance of supportive teachers, while some highlight the detrimental effect that the opposite can have. Paige describes why Miss L was her favourite teacher at primary school: “she used to, like, deal with a lot of stuff when I was there. Like, when I was having bad days, I’d just go to Miss L and she’d sort it,” (Paige, lines 142-143). Paige credits her teacher with having the power to transform “bad days” into good ones and in so doing, gives her the security and comfort that she seeks when her sister is unwell.

Ella describes staff organising a non-uniform day at school to raise awareness of her sister’s medical condition: “they [her classmates] understood what was happening at home because, erm, mum had told the school so then, on, in October, they had a day where you, where you wear purple mufti, sort of to raise awareness,” (Ella, lines 101-103). This event led to Ella feeling that her classmates “understood what was happening at home”, presumably a reference to having a sister with CMN. It is noteworthy that Ella avoids explicitly naming what it was her mum “had told the school”, and what was “happening at home”, suggesting that she may find it difficult to articulate, even though it seems to be a comfort to her that her teachers and classmates know about it.

Anna found the change of teacher at the start of each new school year a challenge at primary school: “Um, it got really sad at the end of the years when I had to say goodbye to my teachers, um, because I would remember all the times that we had with them teaching and helping me,” (Anna, lines 73-75).

Not all participants had overwhelmingly positive experiences of teachers. Mallory recounts a negative encounter with a particular teacher at her school:

> I’ve had teachers tell me that my mum were being lazy for not getting me the right jumper, and compare my home life with Knox to her home life with her son, and tell me that I were over-exaggerating about his epilepsy and all this. […] It was a DT teacher, she didn’t even teach me, it were a technology teacher. Erm, she didn’t even teach me, she just saw me in the corridor before an exam, and obviously it were right before an exam so it bothered [me] through the exam as well. (Mallory, lines 135-141)

This encounter with a single teacher seems to have affected Mallory's perception of teachers generally, as she initially implies that multiple teachers have spoken to her in this way, "I've had teachers tell me", before clarifying that it was a lone "DT teacher". By repeating the phrase, "she didn't even teach me", Mallory relays her fury at being told off and insinuates that the teacher did not know her or anything about her. Nevertheless, the incident affected her throughout an exam and evidently continues to affect her and her perception of teachers generally.

Participants tended to have more positive relationships with teachers in primary than in secondary school. Referring to teachers at primary school, Zack explains: "they were, they were helpful, and they just weren't shouting all the time, they'd try to understand people instead of just yelling at them," (Zack, lines 51-52). From this, we can infer that Zack's experience of teachers at secondary school has been somewhat different; he implies that teachers do not try to understand pupils and shout at them instead. The repetition of "just" and the contrast with his experience of "helpful" teachers in primary school convey Zack's frustration at his experience of teachers in secondary school, without even naming it.

Daisy encapsulates the sentiment of several participants in her description of teachers at secondary school: "I get along with them pretty well. I don't have, like, a close relationship with any of them, it's just that they teach me, I learn, that's basically it, really" (Daisy, 132-133). Daisy's description of a transactional relationship between her and her teachers conveys a lack of rapport and warmth, despite the fact that she "get[s] along with them pretty well". There is a sense that, while this sort of interaction between teachers and pupils is fine for most pupils most of the time, for siblings of a child with CMN, there may be occasions when they need more compassion and trust; more of the “close relationship” which Daisy points out that she lacks.

4.5.2 Superordinate theme 3.2: The impact of relationships with peers

Friendship plays an important role in the lives of siblings of children with CMN. Being able to spend time with friends is the only positive aspect of school for Mallory: “I do like seeing my friends, I mean, it is nice to see them, but I’d say that’s about it, really, to be honest, I just can’t wait to leave,” (Mallory, lines 152-153). Mallory gives the impression that friends are one of the few, if not only, pull factors keeping her in school.

Zack’s overriding memory of primary school is of the friends he had there:

> Well, primary school was… I quite enjoyed it really. It was, it was like, I don’t really remember it much. I remember it being quite good though, like, I had a lot of friends that I was happy with, and we’d always be doing stuff together, and I was getting good grades and stuff. And that’s pretty much it. (Zack, lines 43-46)

Zack’s memory of primary school is dominated by friendships. In contrast, at secondary school, he initially experienced bullying: “the first two years I had issues with a bit of bullying by, yeah, a few people, then after, after like COVID hit, it, it kinda just settled a bit,” (Zack, lines 75-77). Zack believes that bullying no longer takes place within his year group and he puts this down to pupils having a better knowledge and understanding of one another:

> […] now we’ve all kind of settled with our own friend groups, we know where each other, well, we know who everyone is now, and we’ve kinda just grown to know all, everyone, and all the people in our year so we know what they’re like. (Zack, lines 136-138)

Being settled with a group of friends acts as a protective factor for Zack, and bullying seems to be a thing of the past. Daisy’s friends play a similar role for her against the judgement of others: “I sometimes feel like, I guess, I’m being judged sometimes by certain people, but I’ve got my friends with me, so that helps a lot," (Daisy, lines 120-122). She attributes some of the difficulties she experiences to with her peers to attending a same-sex school:

> It's an all-girls school so rumours spread a lot, and you always hear people talking about other people, so like, when I'm walking, I'll hear people behind me and then they laugh and I'll be, like, are they laughing at me, or something funny they saw? (Daisy, lines 125-128)

The rhetorical question Daisy poses conveys the unease she feels walking around school; it is unclear whether she is being laughed at, and it is uncomfortable to think that she may be, particularly given the additional challenges and responsibilities she faces as the sibling of a child with CMN. Daisy acknowledges they may not be laughing at her, but the uncertainty itself is disconcerting.

4.5.3 Superordinate theme 3.3: Others don't understand

While Mallory's friends provide a reason for her to attend school, she does not feel that they really grasp how difficult her living circumstances are:

> I have got, like, good friends, but, I mean, they don't really get it. When I'm telling them, when I tell them, they don't really get it, and they just think Knox's like, funny, sort of thing. They don't really actually sort of understand the depth of it. (Mallory, lines 201-203)

The idea that Mallory's friends find her brother "funny" comes in stark contrast to the reality of the life with him that Mallory has described. The phrase "depth of it" suggests the profound impact that living with a sibling with CMN has had on her life, making it all the more striking that she feels so ill-understood.

It is not only peers who do not understand; participants also speak of teachers who seem to lack curiosity or empathy for siblings of children with CMN:

> For me, personally, I'd like a bit more, like, understanding towards home life. Not many people know what happens outside of school. They just kind of think everything's going fine and there's no problems, but then, yeah, teachers and staff and then other people just don't realise it. (Zack, lines 195-197)

> I think they should actually consider what might be going on, like, they never ask about anything, erm, they don't, when you explain what's going on, they don't seem bothered, or they don't try and listen or they don't act like they understand or anything. They just pretend that you're not even there. (Mallory, lines 252-255)

Mallory reports feeling ignored by teachers. Even when she tells them what is happening, they do not seem to try to understand or hear her, and this appears to leave her feeling isolated and powerless. She goes on to describe a school receptionist who "shut the door on me so I can't talk to them [school mentors]" (Mallory, line 257), conveying not only a perceived psychological barrier but an actual physical barrier being put up between her and someone who might have been able to listen and empathise with her. Mallory's experience at school also reflects a broader concern that no one (other than her mother) comprehends the struggles she faces: "I mean, family come, but then they go and just say, oh yeah, 'Knox's such a pain, he's so funny', and they just find it funny, they don't actually understand," (Mallory, lines 205-207). It is concerning that even extended family members appear to laugh at the challenges Mallory experiences with her brother, adding to the feeling of isolation and helplessness.

Zack is not only concerned by the lack of understanding about the challenges faced by siblings of children with CMN; he also seeks to advocate for his sister with CMN and other children and young people with SEND: "Teachers need to have a better knowledge and understanding of, like, the needs. Not, not many teachers in schools actually know, like, what autism and ADHD and stuff like that is" (Zack, lines 143-144).

Paige feels that school affects her time with her sibling and perceives that others do not believe it should: “I wouldn’t say it [school] does [affect my time with Moo], but I feel like it does. But from other people’s views, I don’t think it, like, they don’t think it, like, should” (Paige, lines 240-241). This subtle indication that Paige feels other people’s views differ from her own echoes the views expressed by other participants that other people do not truly grasp the experiences of siblings of children with CMN.

4.5.4 Summary of ‘The Importance of Relationships at School’

The master theme, ‘The Importance of Relationships at School’, comprised the importance of teachers and friends, the impact of negative interactions with staff and peers, and the lack of understanding by most people. Supportive teachers were key to a positive school experience; favourite teachers had the ability to turn a bad day into a good one, whereas unsupportive teachers had a detrimental effect on siblings of children with CMN. Friends could motivate siblings to attend school and were a protective factor against bullying and judgemental peers. However, friends, school staff and even extended family did not understand the challenges experienced by siblings of children with CMN.

4.6 Master theme 4: Aspects of School That Help and Hinder

The master theme, ‘Aspects of School That Help and Hinder’, comprises all school-related themes other than relationships. These are: ‘The question of homework’, ‘Extra-curricular activities – time for me’, ‘The best parts of school for me’, ‘School rules and policies can help or hinder’ and ‘When I least enjoy school’ (see Figure 4.5). Table 4.4 presents the participants who informed each of these superordinate themes and the ensuing sub-sections explore their concerns in detail.

Figure 4.5

Superordinate themes linked to 'Aspects of School That Help and Hinder'

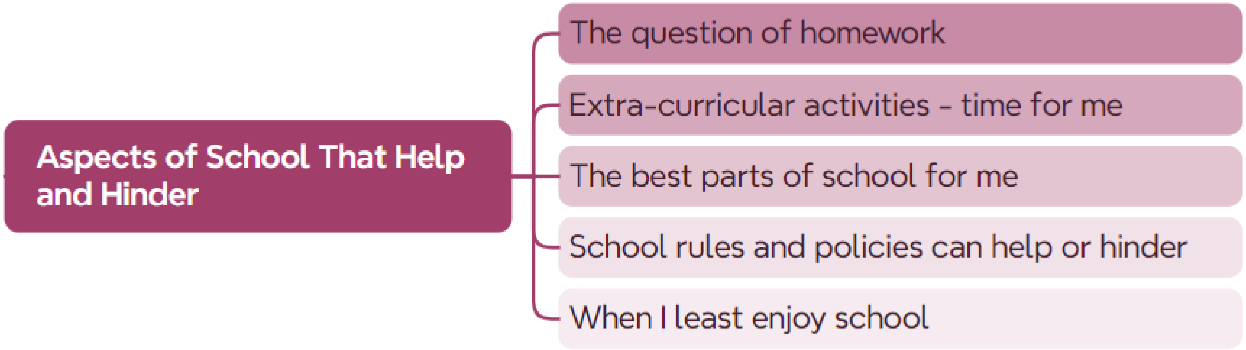


Table 4.4

Participants who spoke about 'Aspects of School That Help and Hinder'

	Paige	Daisy	Ella	Mallory	Anna	Zack
The question of homework		✓	✓	✓	✓	✓
Extra-curricular activities – time for me	✓	✓	✓		✓	✓
The best parts of school for me	✓		✓	✓	✓	✓
School rules and policies can help or hinder	✓			✓		
When I least enjoy school	✓			✓	✓	

4.6.1 Superordinate theme 4.1: The question of homework

On the whole, Ella reports having had a positive experience of homework:

> […] in Year 6 I started getting homework along with having to help out around home, but I managed, school made it so that it wasn't desperately hard homework, it was just easy, gradual homework, so yeah, that was helpful as well. (Ella, lines 78-81)

Ella explains that the introduction of homework in Year 6 coincided with an increase in responsibilities at home, yet she was able to manage them both because of the school's approach.

Having plenty of time to complete homework, or advance warning about it being set seems to help siblings plan and manage it best: "this year, um, the homework has evened out, and they've put, um, they give you heads up when the homework is due and it's easier for me to know when they're due," (Anna, lines 155-156). This is particularly helpful as Anna's sibling with CMN will sometimes divert her attention away from her homework:

> [S]ometimes, when she didn't get what she wanted, or, like, she wanted to play with me but I said no, she, um, would throw a bit of a tantrum and, um, distract me so I couldn't do my homework and I would have to play with her. (Anna, lines 177-179)

Anna's hesitation, "um", before she describes her sister's behaviour suggests a reluctance to blame her and a desire to portray her sister in the best possible light. Anna also describes trying to satisfy her sister's curiosity about her homework by explaining it to her but realises that this is not always possible:

> One time, she was like, 'what's that?' And I said, it's algebra'. And she said, 'alge-what?'. And I said, 'algebra, it's, um, when you use *a* times *a* is *a* squared'. And she said, 'what?'. So I said, 'don't worry'. Um, so she doesn't understand sometimes, but her homework does get her, I would say, help her in life a lot, so she is way further than she was at the start of the year. (Anna, lines 187-189)

Anna's patience and love for her sister shine through as she recounts having tried to explain complex mathematical concepts to her. Despite her sister not understanding in this instance, Anna can see the progress her sister has made and the role that homework has played in this.

Daisy is less positive about homework and the consequences for not doing it:

> [I]f you don't do your homework you instantly get behaviour points, and if you don't do it after a few times then you'll get detention and stuff, and some people just don't have the time or the energy to do it and it's just unfair. (Daisy, lines 212-215)

Daisy implies that not enough consideration is given to the home lives of pupils where homework is concerned, leading to further consequences which she finds unfair. Similarly, Mallory does not feel able to complete homework due to her family circumstances, even when the requirements may seem reasonable to others: "to anyone who doesn't live in this scenario, it doesn't sound like a lot, it's only 40 minutes, but I haven't got the time, especially when I'm this tired and sleep-deprived" (Mallory, lines 306-307). Mallory's acknowledgement that "it doesn't sound like a lot" highlights one of the difficulties faced by siblings of children with CMN; this amount of homework may not be a lot for pupils under *normal* circumstances, but siblings of children with CMN are living in *extraordinary* circumstances, and at times their additional stressors and responsibilities make completing homework more of a challenge that it may seem to be on the surface.

4.6.2 Superordinate theme 4.2: Extra-curricular activities – time for me

Extra-curricular activities play an important role in the lives of siblings of children with CMN, giving them the space and time to pursue their own interests outside of home and the classroom. Nevertheless, they often come at a cost.

Paige previously attended art therapy sessions which she found helpful:

> I used to have a private art therapy teacher and it really helps. Like, we used to just sit there and fidget, and play with slime, and like, kinetic sand, and stuff, like art, we used to paint and draw (Paige, lines 330-332)

Unfortunately, Paige had to stop these sessions due to the financial cost, but the impact they had on her is clear from the range of activities she recalls and her use of the present tense to describe their impact, “it really helps”.

Anna enjoys singing, dance and drama, describing the “big production […] big performance” (Anna, line 145) she is participating in. Daisy explains why she too is such a fan of creative arts:

> I just like being able to act out things and to, like, express, like myself in a different way than just… ‘cause I like writing as well, so I write poetry. Recently I’ve been interested in, like, that, but being able to act has given me another form of expressing myself (Daisy, lines 108-111)

Acting and writing poetry give Daisy an opportunity to express herself in unique ways. She interrupts her flow when comparing acting to other means of expression: “in a different way than just…”. By leaving the sentence unfinished, she demonstrates the inadequacy of words alone to express her innermost thoughts and feelings, underscoring the draw for her of other creative forms of expression.

While Zack enjoys participating in sports clubs, he also recognises the impact this has on the time he spends with his sister:

> […] with, like, after-school clubs now in Year 11 and stuff, I spend a lot of time at school after hours, doing extra stuff, which, some days I won’t be back ‘til like six o’clock, or like, maybe half six, for, like, school football matches and other clubs, which like, in the evenings, you just don’t get that time to see each other, you know? (Zack, lines 117-120)

For Zack, there is a conflict between taking part in extra-curricular activities and spending time with his sister, and he seems to feel guilty for taking the time to do activities he enjoys. By rhetorically asking, “you know?”, Zack may be seeking acknowledgement of his dilemma and approval of his choice to attend the after-school clubs.

4.6.3 Superordinate theme 4.3: The best parts of school for me

Participants describe the elements they like most about school. For some, this is particular subjects, such as Ella, whose favourite subjects include English, which she describes as “quite calm, so, the classroom is very nice and then the teacher makes it so it’s slowly, gradually building up on information, and not like suddenly all in once” (Ella, lines 152-153). Ella appreciates subjects in which the teacher relays information clearly and gradually, avoiding overwhelming her with too much new information all at once.

For others, including Anna, school trips are a highlight of their school experience: “when we go on, like, a trip to somewhere and we have a load of fun, like, the zoo or something” (Anna, lines 91-92).

Generally, participants speak more positively about primary school than secondary school, for example, “it were just so much better, they didn’t expect that much of you, and people actually cared, a lot more than they do now anyway,” (Mallory, lines 246-248).

Anna also speaks positively about the “really good community” (Anna, line 64) at her primary school, explaining that:

> […] whenever someone was sad or hurt themselves, um, a lot of people would say, ‘are you okay?’ or ‘what’s happened? Are you alright?’ or ‘do you need any help?’. And then, everyone would be there for everyone, and it was a really sweet bond between school. (Anna, lines 68-70)

It is interesting that Anna describes the “community” feel of her school in terms of how people would act in times of difficulty, “whenever someone was sad or hurt themselves”. This may be indicative of her experience of pupils and teachers showing care and compassion in times of obvious need, rather than when, on the surface at least, everything seems to be fine.

For similar reasons, Paige enjoys going to a small secondary school:

> “as it’s quite a small school, it’s like, really like, it’s like the whole thing is quite kind and caring, there’s no, like, bullying there or anything. And it’s like a really good school,” (Paige, lines 124-126).

As well as the lack of bullying and small size of the setting, Paige appreciates the diversity of needs in her school and how well the school meets these needs:

> [T]here’s loads of people with like, special needs and they take care of them, and people with, like, autism and ADHD and epilepsy and stuff like that. There’s a lot of people there and they all, like, relate to each other. Everyone’s got something. So they’re not all perfect. (Paige, lines 189-192)

Paige relays feeling a sense of connection and belonging at her new school because she is better able to relate to her peers who, from her perspective, have all “got something”, and therefore there is less pressure to be or appear to be “perfect”.

Zack values the range of cultures and ethnicities represented by pupils at his school:

> […] probably all the, like, people that I’ve met that I’d never met before, just like getting to know people, like, from everywhere, and, not people, not just people from this country and other people that have come from other places, and it’s like, cool to know their background and stuff. (Zack, lines 97-99).

Zack and Paige indicate that, as siblings of children with CMN, they have an enhanced appreciation of people who are different to them. Having grown up with a brother or sister with a range of needs, they are exposed to both the challenges and benefits they have to offer and have therefore learnt to value and appreciate diversity in a multitude of forms.

4.6.4 Superordinate theme 4.4: School rules and policies can help or hinder

Paige and Mallory both speak about school rules and policies which can either help or hinder their school experience. Mallory explains the school's procedure when she is late, the consequence of which is an after-school detention. However, this poses additional to challenges to her as the sibling of a child with CMN:

> My mum's explained to them that I can't go, that I haven't really got time to go, and that she can't be, she hasn't really got the time to be worrying about me walking home in the dark because obviously, if anything were to happen, she couldn't make it up there because she's got Knox. (Mallory, lines 288-291)

Nevertheless, according to the school rules, Mallory faces a consequence for missing a detention:

> I mean, then you go into isolation for the day, so the lessons that they claim are so important, actually you don't get to do because they put you in isolation just for being 10, 15 minutes late, or sometimes it's 2 hours late, but either way, I just still think they should be more considerate. (Mallory, lines 293-296)

Mallory questions the logic behind having to miss a day of lessons as punishment for missing a detention that was issued for being a few minutes late to school. Ultimately, she believes her school "should be more considerate" of her circumstances to help prevent this negative spiral. While Mallory's brother has improved since he has been on medication and his seizures at night are less frequent so she is less often late to school, she describes that "there were a time when he had 3 to 4, like, 300 seizures a day" (Mallory, line 300). Mallory highlights how rules which may work as a deterrent for most pupils, unfairly punish siblings of children with CMN when they have good reason for arriving late to school.

In contrast to Mallory, Paige feels the rules at her new school are fair and serve the pupils well: "the school I'm at now is, like, a really kind school. There's no tolerance of bullying.

It’s like, it’s not strict, but it’s got its policies” (Paige, lines 160-162). Paige sees value in the rules and highlights the positive impact they can have, particularly when compared to her previous school:

> Like, in R school, you keep your phone but you’re not allowed to go on it, but people do ‘cause you know, they break rules, but in the school I’m at now, which is H school, which I’m wearing right now [shows badge on blazer], you have to hand in your phone every morning and I think it’s really good ‘cause then you don’t get carried away with social media. (Paige, lines 162-165)

Paige appears to take pride in being a pupil at her current school, pointing out her uniform and presenting the rules favourably in comparison to those at her previous school. She acknowledges that some people “break rules” and that measures are necessary to prevent this happening. Paige appreciates having rules and policies in place as she can see how they support her own safety and wellbeing at school. In contrast, for Mallory, certain rules stand in the way of her wellbeing and increase her stress in already challenging circumstances.

4.6.5 Superordinate theme 4.5: When I least enjoy school

Participants who have had negative experiences of a school find it difficult to think of anything positive about it. For instance, Paige has recently moved school due to difficulties at her previous one, and draws comparisons between her own and others’ experience of it:

> Well, I went to R school, for a…, I think it was for a year, yeah, and it just wasn’t, it wasn’t fitting for me, I didn’t like it there. Loads of people have moved from there that I know because they didn’t like it at all. (Paige, lines 167-169)

By pointing out that lots of other pupils have also left the school, Paige indicates that she is not alone in condemning the school. Likewise, Mallory struggles to think of any positive experiences from her time at secondary school: “I mean, I’ve got loads of bad times; I can’t really think of any, like, nice ones, really,” (Mallory, line 173).

Although Anna's experience has been broadly positive, she talks about ethics and philosophy being her least favourite subject:

> [....] because, um, we don't really do a lot in the lessons of those, because all we do is either Christianity or Buddhism. Um, I do like those subjects but we've done it a lot so I feel like we should move on a bit. (Anna, lines 151-153)

It is not so much the content of the lessons but rather the repetition of what is taught that Anna dislikes. Anna explains that she does in fact "like those subjects" and makes a reasonable case for needing to "move on" to new subject content.

On the whole, participants were positive about most aspects of school and did not readily seek to criticise their school. Nevertheless, where negative opinions arose, such as in Paige and Mallory's case, participants had either left, or wished to leave, the school, indicating a complete breakdown in the relationship between the participant and the school.

4.6.6 Summary of 'Aspects of School That Help and Hinder'

Well siblings described aspects of school that helped or hindered them. Homework could be manageable if set well in advance of the deadline but some well some found it hard to complete due to their home circumstances, and the consequences were deemed unfair. Extra-curricular activities afforded well siblings the time and space to pursue their own interests but cut down the time available to spend with siblings with CMN. Well-paced teaching, the primary school experience, a close-knit community, school trips and diversity were aspects of school that well siblings particularly appreciated. The rules around being late to school were regarded as illogical while other rules were seen as supporting pupils' wellbeing. While, on the whole, well siblings had positive experiences, those who did not enjoy school struggled to find anything positive to say about it.

4.7 Master theme 5: Time for Change

The final master theme, ‘Time for Change’, encompasses far-reaching comments by all participants which relate to the transient nature of time. The superordinate themes which fall within this are ‘Times of transition can be challenging’, ‘My hopes and wishes for the future’, ‘Nothing stays the same’ and ‘My idea of an ideal school’, as set out in Figure 4.6. Information about which participants informed each of the superordinate themes is displayed in Table 4.5.

Figure 4.6

Superordinate themes linked to ‘Time for Change’

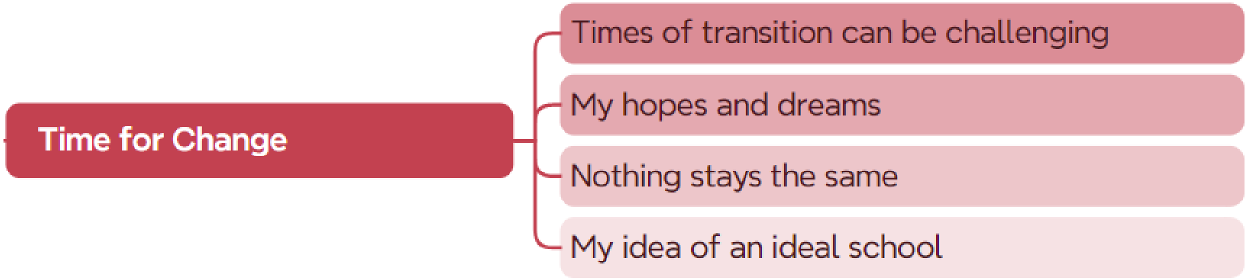


Table 4.5

Participants who spoke about ‘Time for Change’

	Paige	Daisy	Ella	Mallory	Anna	Zack
Times of transition can be challenging			✓		✓	
My hopes and wishes for the future		✓		✓		
Nothing stays the same			✓	✓		
My idea of an ideal school	✓	✓	✓	✓	✓	✓

4.7.1 Superordinate theme 5.1: Times of transition can be challenging

Two of the participants who have started secondary school relatively recently, Ella and Anna, speak about the transition there from primary school. Ella explains what helped her:

> [O]n the first day of school it was just Year 7 and the sixth formers there, so it was, it was like a day to settle and get to our classes, we didn't know how to get to our classes properly. So, it wasn't too hectic to handle but then it was also quite calming as well, so it wasn't too much suddenly all at once, (Ella, lines 140-144)

Ella's description of the transition suggests it was well planned and helped ease pupils into their new routine. The use of phrases in the negative, such as "it wasn't too hectic" and "it wasn't too much suddenly all at once", suggest an alternative reality that was avoided through care and consideration.

Anna describes the transition as:

> […] a big leap from primary school to secondary school because there was like 120 kids in one school and then a big leap to about just over 2,000 kids. Um, and it was a big leap but I got used to it and, when you overthink, it sounds really bad, but it wasn't that bad when I got there. (Anna, lines 116-119)

By repeating "a big leap", Anna highlights the enormity of the move for her, underlined by the jump in the number of pupils, demonstrating the extent of the change. Anna recognises that the thought of moving to secondary was worse than the reality of it.

4.7.2 Superordinate theme 5.2: My hopes and wishes for the future

Daisy and Mallory speak about their dreams for the future. As well as hoping to become "an actress" (Daisy, line 111) in the future, Daisy hopes for more quality time with her mum:

> I'd probably go shopping with her because we both enjoy shopping and we've been… we went to London to see the, er, in the West End, to see Moulin Rouge, so I think going to London with her would be nice, or seeing a concert or something, that kind of thing. (Daisy, lines 54-57)

The simplicity of Daisy's wish to "go shopping" with her mum if she had more time with her underscores the challenge of being the sibling of a child with CMN; such a run-of-the-mill activity becomes a luxury.

Mallory's hopes for the future centre around her ambitions of improving the system for pupils with needs like her brother's:

> I want to, it's quite strange actually that I want to go back to school, but I want to be a SENCO, erm, 'cause I've seen how much Knox has struggled with it and how much they didn't, like, listen to us, so, yeah, I want to make it better. (Mallory, lines 155-157).

Mallory positions herself alongside her mother, as if she were Knox's parent rather than his sibling, when she says "they didn't, like, listen to us". She gives the conveys that she has tried to fight and advocate for her brother's needs to be met, and recognises that, with everything she has said about her school, it may seem surprising that she wishes to work in one. However, Mallory explains that, motivated by the difficulties she has seen her brother face, she has a desire "to make it better" for children in the future.

4.7.3 Superordinate theme 5.3: Nothing stays the same

Ella describes having grown closer to Starla, her sister with CMN, over time, explaining that, "I've spent more time with her and I've gotten to know her better than I'd of course known her in the first few years of her life, so I think that would be why," (Ella, lines 21-22). Although Ella points out the inevitability ("of course") of getting to know someone better over time, there is a sense that over time, Ella has gotten to know her sister better and her personality beyond simply a child with CMN.

Both Mallory and Ella indicate that there really is no such thing as a 'typical day' in the life of a sibling of a child with CMN: "it changes but a typical day can be quite hectic in the morning and then, like before school and that, and then we get to like the evening and it can sometimes be noisy or quite calm," (Ella, lines 49-51), and:

> […] they're all different really, I can't really tell you, like, a typical day because they're all different. I mean, some days he'll wake up absolutely fine, some days he'll wake up really sad or really angry, erm, we just, our days sort of go off Knox, (Mallory, lines 94-96)

Thus, a day in the life of siblings of a child with CMN can vary dramatically depending on their brother or sister, as well as other factors. Ella and Mallory's comments highlight the uncertainty and instability inherent in their everyday lives. Furthermore, Ella describes how much life is changing as she grows older:

> I'm gonna be 12 next year, so, it's getting to that age where things are changing everywhere and I see the world different, so they [my parents] are very helpful with that, and like understanding it, because sometimes it can be difficult to understand, but they're very helpful with that. (Ella, lines 38-40)

Ella emphasises how helpful her parents are to her as she grows up and develops a more mature understanding of the world around her, reminding us of the everyday challenges of being an adolescent, even without the added complication of having a brother or sister with CMN.

For Mallory, life changed dramatically as her brother got older and his needs became more apparent: "when he came along, he were like the cutest baby ever, erm, and then, like, after a while, he just, everything sort of changed, he'd like, start to get angry, especially towards me," (Mallory, lines 3-5). Mallory's description of the changes in her brother highlights the potential for sudden, unexpected changes to occur in the lives of siblings of children with CMN.

4.7.4 Superordinate theme 5.4: My idea of an ideal school

In line with the fourth research question, participants were asked explicitly to describe their ideal school. This superordinate theme encompasses those responses, as well as other relevant statements made throughout the interviews.

When participants were asked to describe their ideal school, several of them spoke about a school that meets the needs of children with SEND, highlighting their prioritisation of the needs of their siblings with CMN over their own. For example, Paige explains, "I think, if I was to make a school, I'd probably make, either a primary school or a nursery school, but I'd make it for people probably with special needs," (Paige, lines 258-259).

While Zack also describes his ideal school as one which meets pupils' additional needs, he puts the emphasis on people respecting one another:

> probably where, like, everyone is, is nice to each other, they, they're understanding towards other people's needs, and like, not everyone's the same, and they're…some people need more support than others in, other, different, like, areas, and people need to be respectful towards that and understand that people, people are different. (Zack, lines 123-126)

Furthermore, Anna explains:

> I would describe my ideal school, um, a school when they would, like, help children in need, so, um, like my school, but, with, it's like my school with Sarah's school mixed together. So, they would help a lot with Sarah and would help a lot with me. (Anna, lines 201-203)

Similarly, Ella's ideal school would be:

> a place of, like, more understanding, a little bit more understanding of like how children can have, like, the pupils can have siblings who affect, not only just the parents but then also the sibling, so it will affect, the child with extra needs, their sibling, which can then affect school and then affect everything, so that could happen. (Ella, lines 220-223)

Ella's conception of her ideal school acknowledges that a child's needs can affect their parents, their siblings, their own and their siblings' school, in fact, "everything".

Zack describes a school which would "give, like, time towards the siblings, and get teachers to actually talk to them about what happens so they have a place where they can go and speak," (Zack, lines 162-163).

To Daisy, it is important that pupils can express themselves freely without fear of being judged: "I'd like that, where no one can really… everyone can just express themselves, and where you can have fun without feeling like other people are going to laugh at you for having fun," (Daisy, lines 171-173).

Both Paige and Daisy describe teachers at their ideal school who would ask questions without prying:

> [T]hey would ask how your day is, but they wouldn't ask, like, if you were to say something's bothering you, they wouldn't ask what until you tell them what's going on because they don't want to invade your space. I'd have teachers like that. (Paige, lines 274-276)

> [Y]ou'd ask them if it's alright if you give them [homework] in at another, at a later date, and they'll… and the teachers will be like, 'alright', and they won't question it as much either, you won't have a full-on interrogation about why you won't be able to hand your homework in. (Daisy, lines 217-220)

Paige and Daisy do not want teachers to ask more questions than they are willing to answer. Paige wishes teachers would show an interest in her day without "invad[ing] your space" and Daisy wishes to be able to hand in homework late without the need for "a full-on interrogation", implying that in their current schools, this is what happens.

While most participants talked about changing aspects of their secondary schools, Mallory described her ideal school as being like her primary school: "Erm, I'd have a few of my old teachers back, yeah, I'd probably just go back to primary school actually," (Mallory, lines 241-242).

Ella describes teachers allowing pupils to have extensions for homework at her ideal school:

> […] say there's, something's going on at home, um, it's, the child feels more like they can just go up to the teacher and ask, can they have a little bit of an extension on like homework time or something, like, when it's due in, because say something's going on at home and you haven't been able to do it, that, I've heard of that happening before, it hasn't happened to me yet, luckily, so, but it might any day. (Ella, lines 214-218)

Ella's final words encapsulate the importance of many aspects of the ideal school for siblings of children with CMN; from teachers who are caring and understanding, and pupils who are non-judgemental, to rules that can be adapted and homework deadlines that can be extended; they may not have been needed yet, luckily, but they might be any day.

4.7.5 Summary of 'Time for Change'

'Time for change' covers the transition from primary to secondary school, the hopes and wishes of well siblings, changes inherent in the lives of siblings with CMN and visions of an ideal school. The move from primary to secondary was found to be not as scary as feared. Participants hoped to spend more time with parents in the future, as well as having ambitions to improve the education system for pupils with a high level of need. Well siblings acknowledged changes that occurred as they and their siblings with CMN grew up, and no two days in their lives were the same. Well siblings conceptualised their ideal school as one that met the needs of all pupils with SEND, where staff and pupils were more understanding, where they could express themselves without judgement and teachers asked the right level of questions.

4.8 Chapter summary

In this chapter, the findings from interviews with six siblings of children with CMN were presented using IPA. Five master themes derived from the data were explored to determine the commonalities and unique aspects of the lived experiences of siblings of children with CMN. They were: ‘My Family Life’, ‘My Growth and Development’, ‘The Importance of Relationships at School’, ‘Aspects of School That Help and Hinder’ and ‘Time for Change’. The following chapter entails a discussion of the findings in relation to the research questions, drawing on the existing research base and reflecting on how findings from the current study can be applied in schools and to EP practice to better meet the needs of siblings of children with CMN.

Chapter 5: Discussion

5.1 Chapter outline

The previous chapter presented the findings from interviews with six siblings of children with CMN using IPA. In the current chapter, the findings relevant to each research question are presented in the light of existing literature and psychological theory. A critique of the current research is undertaken and potential avenues for the dissemination of the research findings are explored. Implications for schools, EP practice and future research are considered followed by the researcher's reflections on the research process and concluding comments.

5.2 Research aims and research questions

The research aimed to explore how siblings of children with CMN experience family life and school. Furthermore, it sought to develop recommendations for schools and EPs to support siblings of children with CMN.

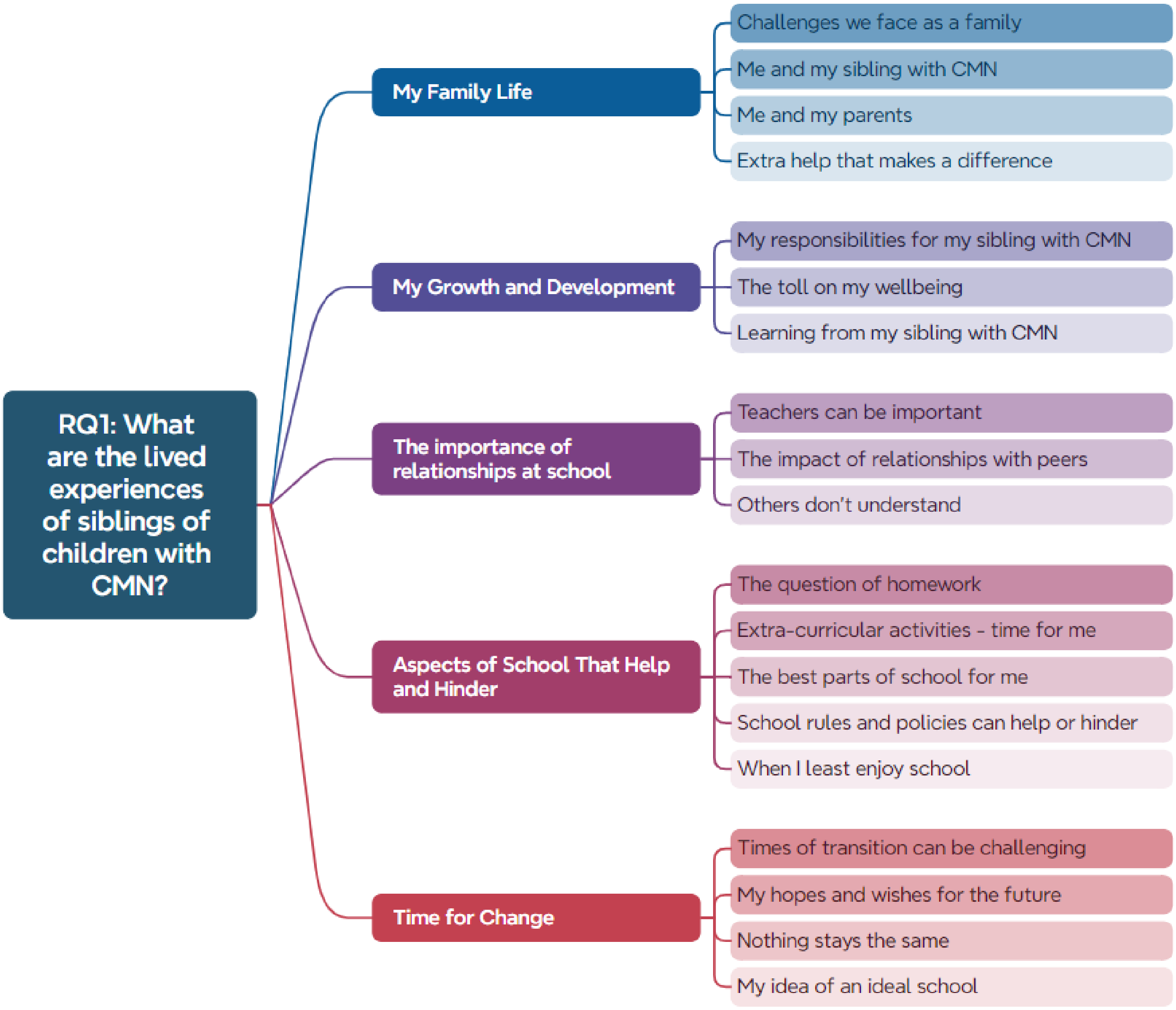
The research set out to address four research questions: the over-arching research question, what are the lived experiences of siblings of children and young people with CMN? (RQ1) and three sub-research questions: how do siblings of children and young people with CMN experience family life? (RQ2); how do siblings of children and young people with CMN experience school? (RQ3); and how do siblings of children with CMN envisage their ideal school? (RQ4). In an attempt to answer these questions, individual semi-structured interviews with six siblings of children with CMN were conducted and the data from these interviews were analysed using IPA. In the following section, the research findings are presented in response to each of the research questions, alongside relevant psychological theory and literature review findings. At times, new literature and theories pertinent to the findings are also introduced.

5.2.1 RQ 1: What are the lived experiences of siblings of children with CMN?

All of the findings from the interviews with siblings of children with CMN are deemed to be relevant to the first and main research question, as shown in Figure 5.1. Furthermore, all the findings relate to at least one of the three sub-research questions. Therefore, to avoid duplication, the findings are presented in response to RQ2, RQ3 and RQ4, which together contribute to answering RQ1.

Figure 5.1

Master and superordinate themes from current study relevant to RQ1

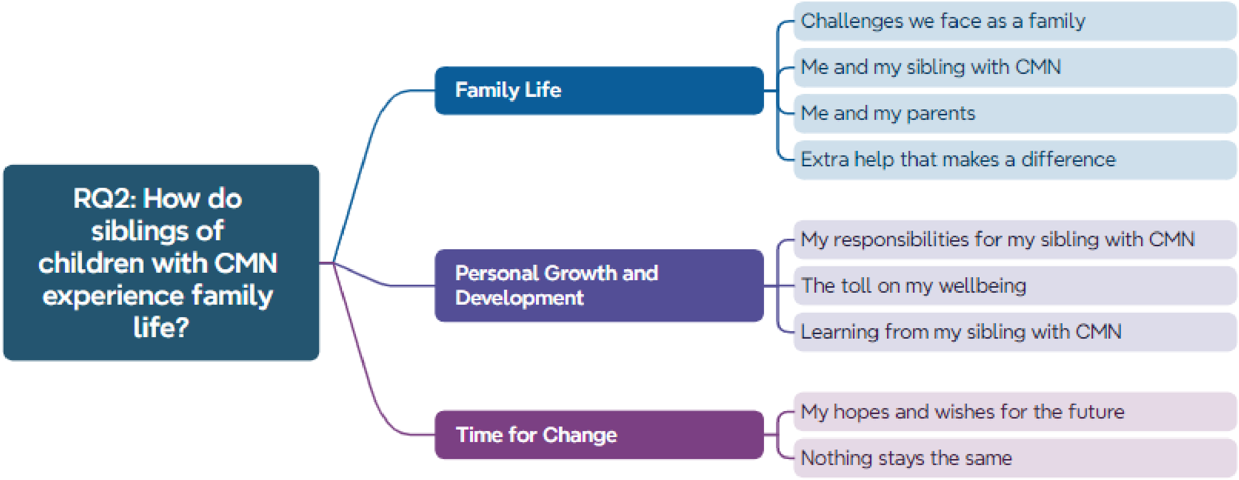


5.2.2 RQ2: How do siblings of children with CMN experience family life?

Figure 5.2 sets out the master and superordinate themes relevant to the second research question, *how do siblings of children and young people with CMN family life?* In the subsequent sections, the current study's findings relating to family life are explored and linked to psychological theory and previous research.

Figure 5.2

Master and superordinate themes from current study relevant to RQ2



5.2.2.1 My Family Life.

5.2.2.1.1 Challenges we face as a family. All superordinate themes related to 'My Family Life' derived from the current study help to answer the second research question as outlined forthwith.

The current research found that siblings of children with CMN experience challenges unique to their circumstances, mirroring previous research. The challenges identified in the current study ranged from witnessing their sibling having seizures and being on the receiving end of violent and aggressive behaviour from their sibling, to seeing their sibling with CMN being poorly treated by peers or dealing with difficult practicalities (e.g. dressing their sibling when they are “floppy”) and their associated emotional effects. These findings have some features in common with previous research, while differing in others. For instance, Haukeland et al. (2015) found that well siblings perceived their lives to be different to those of their peers, which could be accompanied by feelings of frustration or of missing out. Additionally, Malcolm et al. (2014) reported that some siblings were upset by unkindness towards their sibling, in line with the current findings. In contrast to the aforementioned feelings of frustration, other studies have found that siblings were able to accept this difference as a *new normal* (Grant & McNeilly, 2022). Similarly, participants in the current research were accepting of their challenges as typical for their family, but with a clear sense of difference between their own experience and that of other families. This finding is also reflected in the superordinate theme ‘Others don’t understand’, which will be explored later.

5.2.2.1.2 Me and my sibling with CMN. Participants in the current study depicted close, loving relationships with their siblings. Grant and McNeilly (2022) found that being informed about their ill sibling’s condition was important to siblings of children with CMN, and led to them being more patient and accepting of their brother or sister with CMN (Gaab et al., 2014). While participants in the current study did not make an explicit link between their knowledge about their sibling’s condition and their attitude towards them, it could be inferred that their level of understanding – a prerequisite of the study due to the research aims and methods – at least, in part, contributed to their tolerance and acceptance of their sibling with CMN. For instance, one participant described not wanting to change anything about her family because of the happiness her sister brings, despite the chaos.

One participant described the difficulty she experienced in taking her brother out of the house due to his behaviour resulting from his CMN. This echoed Grant and McNeilly's (2022) finding that well siblings of children with CMN avoid social situations that make them feel uncomfortable or cause people to stare. Similarly, Haukeland et al. (2015) found that well siblings could be embarrassed, angered or irritated by their ill sibling's behaviour. It is notable that no participants in the current study explicitly discussed such feelings. Nevertheless, one participant's description of her sibling's behaviour in public suggested feelings of frustration and disappointment at being unable to have a 'normal' relationship or participate in 'normal' activities with her sibling, a finding mirrored in previous research (Brennan et al., 2012; Haukeland et al., 2015). Another participant in the current study expressed surprise that her sister was so pleased to see her after a short stay away. It appeared that she did not expect her sister to remember her and was delighted that she did. Therefore, there was an element of unpredictability in the relationship between participants and their sibling with CMN, with the potential for pleasurable as well as unpleasant effects.

5.2.2.1.3 Me and my parents. The current study found that the relationship between siblings of children with CMN and their parents was overwhelmingly positive, with some participants feeling closer to one parent than the other. In line with previous research (Brennan et al., 2012), some participants expressed a desire for more time with their parents, though there was no sense conveyed, as in the literature, of feeling unimportant, forgotten or even abandoned by their parents (Nolbris et al., 2014) or that limitations were imposed on family life as a result of having a sibling with CMN (Malcolm et al., 2014). On the contrary, participants described finding joy in activities such as dancing around the kitchen with their dad, going for long drives with their mum and being supported by both parents at football matches. This echoes Grant and McNeilly's (2022) finding that siblings of children with CMN feel a sense of accomplishment when activities are completed as a family, which their peers may take for granted.

Consistent with previous research which has found that siblings of children with CMN are significantly more satisfied with communication in the family compared with published norms (Jaaniste, Chin, et al., 2022), participants in the current study seemed to communicate well and readily identify with their parents. By way of example, one participant described her mother as her "best friend", another alluded to her similarity to her dad, being like "two peas in a pod" and another spoke of her shared taste in music and of being "my dad's girl". Furthermore, one participant spoke about her parents helping her a lot, particularly as she was getting older and seeing the world differently, reflecting previous research which describes speaking to family members as a source of comfort for siblings of children with CMN (Jaaniste, Chin, et al., 2022). Although the current research did not explicitly investigate the matter, the findings imply a certain level of satisfaction with communication between siblings of children with CMN and their parents.

Participants in the current study appeared to relate to their parents more so than to anyone else, including siblings and peers. In usual circumstances, typically developing siblings serve as primary socialization agent for each other (Tabor, 2016). However, it appears that siblings with CMN may rely on their parents for socialization, learning as they do to provide care to their sibling with CMN and acting in a more mature, adult-like fashion than in the typical sibling dyad. This appears to strengthen their relationship and leads well siblings to mature more quickly, identifying with their parent more so than with their sibling, as typically developing siblings do. This may be because they share the experience of living with a child with CMN that people outside of the home do not.

Well siblings' relationships with their parents and sibling with CMN may also be considered in light of attachment theory, which posits that a child's emotional connection to their primary caregiver forms the basis of mental representations – their *internal working model* – for all future relationships (Bowlby, 1969, 1973). The *internal working model* has been described as a representation of the self, others and relationships, on which a person's thoughts feelings and behaviours are based in relation to attachment-related situations (Bretherton, 1999). An individual's *internal working model* can have a significant impact on the ability to regulate one's emotions, form relationships, understand social situations and maintain wellbeing (Shaver et al., 2016). Participants in the current study presented as having a secure *internal working model,* therefore being capable of forming healthy attachments, albeit complicated by the atypical development and relationship with their sibling with CMN. This follows research which found that siblings of children with intellectual disabilities were more likely to have a secure attachment style than a sibling control group (Levy-Wasser & Katz, 2004).

5.2.2.1.4 Extra help that makes a difference. The current study found that additional support for children with CMN could provide respite and reassurance to well siblings. Having a carer in the home allowed participants and their parents a break in caring responsibilities. Furthermore, the presence of an additional adult could provide much needed support for the family, while one-to-one support at school for a child with CMN at school could provide comfort and take pressure off their sibling. Hence, those who provide additional support for children with CMN play an important role for siblings, which appears to be a novel finding not present in previous literature.

From an ecological systems perspective, the availability of external carers depends on a variety of factors at various levels of a child's environment. At a microsystemic level, the family may or may not choose to employ or accept professional carers in their home; at an exosystemic level, national and local policies determine if carers are provided by the state; and at a macrosystemic level, the family's socio-economic status will dictate whether or not they can afford to employ professional carers to assist in the home. There may also be influences at the mesosystemic level, such as recommendations made by healthcare professionals or social medial influences, as well as chronosystemic factors, such as which political party is in power and the government's priorities.

Notably, only two participants – from the same family – spoke about the support provided to their sibling with CMN by professional carers, and the respite this gave to them and their parents. It is unclear whether or not the families of the remaining participants received this type of support or if they did but did not speak about it. From a social justice standpoint, it is important that this service is freely available to children of CMN to afford both parents and siblings a break from their caring responsibilities. This is particularly the case given that parents of children with CMN often have to cut back on or give up work altogether, are more likely to struggle to pay the mortgage and experience financial hardship than other families, and incur direct and indirect additional costs associated with caring for an ill child (Thomson et al., 2016).

5.2.2.2 My Growth and Development. The master theme of 'My Growth and Development' encompasses three superordinate themes, all of which are relevant to RQ2.

5.2.2.2.1 Responsibilities related to my sibling with CMN. Participants described caring responsibilities for their siblings, with one participant stating she felt more like a carer than a sibling to her sister with CMN and another feeling like she had to act more like an adult than a sibling of the child with CMN. While previous research has found that siblings were involved in caring for their brother or sister with CMN, this was usually either seen as a source of comfort (Gaab et al., 2014) or pride (Malcolm et al., 2014), or accompanied by a desire to be involved (Grant & McNeilly, 2022). In the current study, the increased responsibility one participant had for keeping her sister with CMN safe seemed to seep unhelpfully into her behaviour around others, while for another, the additional responsibility took its toll in an emotional sense. The current study found that caring responsibilities could take precedence over the well siblings' own needs and wishes and have a negative impact on other aspects of their lives. Thus, the responsibilities associated with having a brother or sister with CMN can affect well siblings physically, emotionally and psychologically, that is, in ways which are not always as positive as previous literature has suggested.

5.2.2.2.2 The toll on my wellbeing. Having a sibling with CMN was found to have a profound effect on the wellbeing of participants in the current study. Disrupted sleep was common among siblings of children with CMN, and this could occur even when there was no actual disturbance present, but rather because they had become so accustomed to being woken up at night, echoing Nolbris et al.'s (2014) finding that well siblings experienced sleeping problems linked to anticipatory grief following their brother or sister's cancer diagnosis.

Furthermore, Mazaheri et al. (2013) also found that siblings of children with Prader-Willi syndrome experienced problems with their sleep.

Participants were upset when they knew their sibling with CMN was not having a good day and worried about them when they were in hospital. Without explicitly stating it, they conveyed a sense of powerlessness and unease about their siblings' illness. These findings are supported by previous research which has demonstrated that worry is prevalent in the lives of siblings of children with CMN (Haukeland et al., 2015; Løkkeberg et al., 2020; Nolbris et al., 2014), negatively affecting their schoolwork and social lives (Malcolm et al., 2014). Other comparable negative emotions experienced by siblings of children with CMN ranged from frustration (Grant & McNeilly, 2022) and anger (Gaab et al., 2014) to helplessness (Nolbris et al., 2014) and sadness (Haukeland et al., 2015). Furthermore, Jaaniste et al. (2022) found that siblings of children with life-limiting conditions had poorer self-reported emotional, social and school functioning than their peers, while Nolbris et al. (2014) found that well siblings felt partly responsible for their sibling's wellbeing.

In addition to the findings in the current study, the identified literature revealed that well siblings could feel angry or fearful when there was a lack of communication about the ill sibling's condition (Gaab et al., 2014) and that the diagnosis of a rare condition could invoke feelings of both sadness and relief in the well sibling (Haukeland et al., 2015). What is more, Brennan et al. (2012) highlighted the use of avoidant strategies such as distraction, resignation and social withdrawal, as coping mechanisms by siblings of children with CMN.

5.2.2.2.3 Learning from my sibling with CMN. The current study identified skills that participants felt they had gained from their experience of having a sibling with CMN, such as patience and an intuition for understanding the needs of others. This echoes previous research which has found that siblings of children with CMN show greater compassion and empathy than their peers (Haukeland et al., 2015; Malcolm et al., 2014) and that growing up with a sibling with an intellectual disability can lead to increased patience, tolerance, love and empathy Dykens (2005). Similarly, Løkkeberg et al.'s (2020) study reported that adolescent siblings of children with cancer gained an increased ability to understand others following their sibling's diagnosis, as well as feeling stronger and more resilient. Moreover, Haukeland et al. (2015) reported that siblings were able to derive positives from difficult situations and that the experience of having a sibling with a rare or severe disorder was enriching.

As well as positive traits and skills associated with being the sibling of a child with CMN, the experience can lead to well siblings developing unhelpful habits. One participant in the current study described having a heightened awareness of safety as a result of growing up with a sibling with CMN. This appeared to have a negative impact on her wellbeing and led her to be extra cautious outside of the home. Løkkeberg et al. (2020) also found that families with a child with CMN had to take extra precautions, which led to well siblings feeling frustrated.

Furthermore, the literature revealed that siblings of children with CMN tended to have a particular appreciation for their own good health and that of other family members (Løkkeberg et al., 2020), as well as the ability of some well siblings to reflect on their own and their family's coping resources, an indication of greater maturity than others of a similar age (Haukeland et al., 2015).

It is noteworthy that some of the findings linked to the personal growth and development of siblings of children with CMN, such as hypervigilance and sleep disturbance, are symptoms which can be associated with traumatic experiences (American Psychiatric Association, 2013). This serves to reinforce the idea, first set out in the introductory chapter, that siblings of CMN may experience their sibling's illness as traumatic, highlighting the psychological impact of having a sibling with CMN and the importance of supporting well siblings effectively in order to mitigate against the development of long-term harmful effects.

However, as well as the negative impact of such experiences, the findings of the current study, backed up by the literature, suggest that siblings of CMN may also learn and grow from their experience, a phenomenon known as *post-traumatic growth* (Tedeschi & Calhoun, 1995). Post-traumatic growth is defined as "positive psychological changes experienced as a result of the struggle with traumatic or highly challenging life circumstances" (Tedeschi et al., 2018, p. 3). Well siblings in the current study appeared to undergo positive psychological changes such as developing patience and compassion, appreciating mutually respectful relationships with family, teachers and friends, and generally adopting a positive outlook on life. It is all the more remarkable that siblings of CMN develop such positive attributes and attitudes given the adverse circumstances they face. Nonetheless, this is precisely what differentiates post-traumatic growth as opposed to normative development: "[t]he struggle that leads to [post-traumatic growth] is not usually at first a struggle to grow or change, but rather to survive or cope" (Tedeschi et al., 2018, p. 5).

5.2.2.3 Time for Change. Two of the superordinate themes linked to 'Time for Change' were relevant to RQ2. These were 'My hopes and wishes for the future' and 'Nothing stays the same'.

5.2.2.3.1 *My hopes and wishes for the future*. Participants in the current study referred to their future career ambitions, one of becoming an actress, and another a SENCo. The latter hopes to improve the education system for children with needs similar to her brother's, motivated by her experience of having seen her brother struggle with a lack of support at school. In line with this finding, a comparative study between adults with a sibling with a developmental disability and those with a sibling with mental illness, the former group was more likely than the latter to report that their choice of career was influenced by their sibling's disability (Seltzer et al., 2005).

The current study also revealed a desire of siblings of children with CMN to spend more time with their parents. One participant spoke of her wish to spend this additional time going shopping, highlighting the challenge that well siblings can encounter doing even simple activities with their parents. Prior research has found that parents of children with intellectual disabilities (Rett syndrome and Down syndrome) recognised and lamented the lack of time they had available for their non affected children (Mulroy et al., 2008).

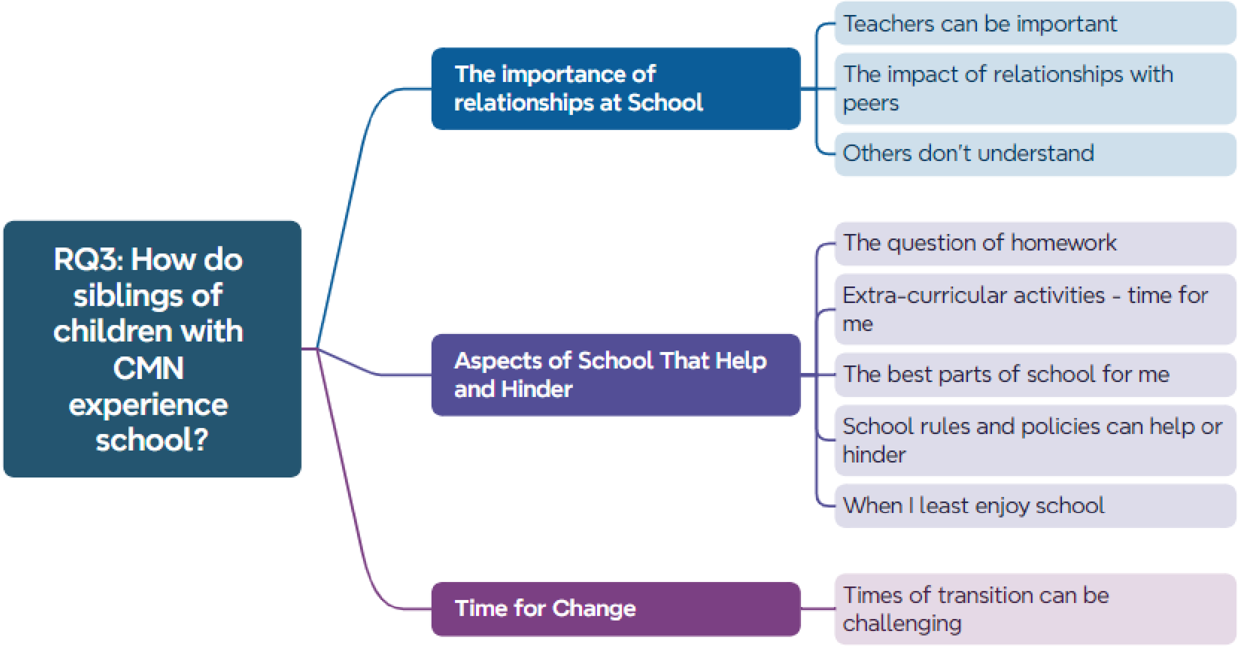
5.2.2.3.2 *Nothing stays the same*. The lives of siblings of children with CMN were found to be prone to change. This could be as a result of growing up and seeing the world through an increasingly mature lens; or growing ever closer to their sibling with CMN; or it could be the consequence of variability in their sibling's health and the resulting implications on their mood and behaviour. Therefore, participants struggled to describe a typical day in their lives because nothing stayed the same. There was a sense that life for siblings of children with CMN entailed a constant possibility of illness and hence, instability.

5.2.3 RQ3: How do siblings of children with CMN experience school?

The master and superordinate themes relevant to the third research question, *how do siblings of children and young people with CMN experience school?*, are set out in Figure 5.3. In the subsequent sections, the current study's findings are explored and linked to psychological theory and previous research.

Figure 5.3

Master and superordinate themes from current study relevant to RQ3



5.2.3.1 The Importance of Relationships at School. The three superordinate themes related to the super-ordinate theme, 'The Importance of Relationships at School' were relevant to RQ3: 'Teachers can be important', 'Friendships and difficult peer interactions' and 'Others don't understand'.

5.2.3.1.1 Teachers can be important. The current study found that supportive teachers were crucial to a positive school experience for siblings of children with CMN. Among the most highly regarded were teachers who were able to comfort well siblings when they were having a bad day, and those who helped to raise awareness of the ill sibling's condition among the well sibling's peers by organising a non-uniform day (with the well sibling's support and parents' permission). Similarly, Løkkeberg et al. (2020) revealed that informing the whole class about a sibling's diagnosis could be comforting for the well sibling, though only if they wanted to do so. Such teachers may help foster a sense of belonging for siblings of children with CMN, helping them to feel accepted, respected, included and supported (Goodenow, 1993). However, notably, others preferred not to share the information for fear of becoming defined by being the sibling of a sick child, and preferred to retain a semblance of normality (Løkkeberg et al., 2020).

Furthermore, the literature states that by informing teachers about a pupil's home situation, schools could ensure that teachers were available to talk to siblings of children with CMN, adapted schoolwork and lowered requirements during periods of difficulty (Løkkeberg et al., 2020). Comforting well siblings and helping to raise awareness of their ill sibling's condition relies on teachers knowing about their home circumstances. In this way, the current findings reflect the existing literature.

This also links to Bronfenbrenner's (1979) ecological systems theory which posits that human development should be understood in the context of interacting systems; what happens outside of the immediate environment, (the microsystem) of the child must also be taken into account. That is to say, while the sibling of a child with CMN is at school, their home environment and any interactions between their parents and teachers (the mesosystem) are relevant to their functioning, as are exosystemic factors, such as their parents' economic situation, which determine the school they attend.

Nevertheless, relationships with teachers at primary school tended to be described in more favourable terms than those at secondary school, a finding not echoed in the literature. It could be hard for participants to say goodbye to teachers in primary school at the end of each school year because of the close relationships that had been built, implying that times of transition were especially tricky for some siblings of children with CMN. Additionally, well siblings were more likely to find teachers at primary school helpful, nurturing and warm. In contrast, teachers at secondary school tended to shout more and were deemed to be less understanding of the challenges faced by siblings of children with CMN, as well as of the needs of pupils with CMN and SEND more generally. These findings appear to be novel.

Following Ainsworth (1989), Kesner describes secure attachment relationships as "long-lasting affectional bonds with a specific caregiver, characterized by active seeking-out of the attachment figure in times of stress with resultant feelings of comfort and security" (2000, p. 134). Well siblings in the current study appeared to portray their relationship with primary school teachers in this light. For instance, teachers provided comfort and understanding, were able to transform a bad day into a good one, and well siblings worried about leaving them when they moved to secondary school. Thus, teachers at primary school appeared to provide a *secure base*[4] for siblings of children with CMN from which they were able to explore unfamiliar

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[4] Following Blatz (1966), Ainsworth (1967, 1978) developed the concept of an attachment figure as a *secure base* during her research of mother-infant relationships in Uganda. It holds that, as children progress beyond infancy, they may develop the security to comfortably explore their environment knowing that their

situations and connect with others, and to which they could return at times of difficulty, fear and loss.

5.2.3.1.2 Friendships and difficult peer interactions. Peer relations were also found to have a significant impact on siblings' school experience. For one participant, being able to see friends was the principal motivating factor for attending school; for another, friends provided protection from the judgement of others. In this way, friends can help to instil a sense of belonging in siblings of children with CMN. The current findings link to existing research which has shown that speaking with close friends could be a source of comfort for well siblings, and that some preferred talking to their peers rather than to adults (Grant & McNeilly, 2022). Furthermore, being active with friends could distract well siblings from thoughts about illness (Løkkeberg et al., 2020) and they appreciated friends who visited or prayed for their ill sibling (Gaab et al., 2014).

Conversely, Løkkeberg et al. (2020) discovered that some well siblings preferred not to bother friends with their concerns and worried that they would push them away by talking about their sibling with CMN. Furthermore, having a sibling with a chronic disorder could result in social activities and peer interactions being restricted (Haukeland et al., 2015).

For another participant in the current study, friends dominated memories of primary school, while early experiences of secondary school were overshadowed by bullying. In each

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parent/caregiver will be there when they return, i.e. using them as a *secure base* (Van Rosmalen et al., 2016). The idea that people in other types of relationship may serve as a *secure base*, such as the therapist to the client or one romantic partner to another, is also widely held (M. S. Ainsworth, 1989).

case, whether positive or negative, peer interactions had the potential to determine the overall perception of the school experience.

In the current study, it was apparent that participants' wished, above all, for kindness. It was important to them to have positive relationships with their peers and teachers, and for others to be kind towards them and their siblings. Participants had fond memories of teachers who had shown them warmth and empathy, and lamented those who had treated them harshly and lacked understanding. They worried about being judged and bullied, and friends served as a protective factor against such interactions.

5.2.3.1.3 Others don't understand. Despite the positive relationships with some staff and fellow pupils, the current study revealed that siblings of children with CMN frequently encountered a lack of understanding from their peers, school staff and wider family. Friends and family could find an ill sibling's behaviour "funny", indicating a deep lack of understanding and empathy. This aligns with previous research which found that well siblings refrained from trying to explain their sibling's illness to their friends for fear they would not understand (Løkkeberg et al., 2020). Moreover, friends claiming to understand their difficulties and experiences could lead well siblings to feel even more isolated and frustrated than before (Løkkeberg et al., 2020).

In general, siblings felt most people, including teachers, lacked curiosity and assumed everything was fine when it may not have been. Some participants expressed that teachers did not listen or assumed everything was fine at home when it was not, leading them to feel unheard and unseen. This echoes previous research which has found that many siblings did not feel they had someone they could talk to openly about their thoughts and feelings (Brennan et al., 2012), even though this is deemed to be important (Nolbris et al., 2014). Nevertheless, others intentionally avoided talking about their ill sibling outside the family home in an attempt to compartmentalise their lives (Brennan et al., 2012; Grant & McNeilly, 2022).

Grant and McNeilly (2022) found that siblings benefited from participating in peer support groups with other siblings of children with CMN, which may have been helpful to participants in the current study since they appeared to lack support outside the immediately family. It is perhaps unsurprising that no participants spoke of any such group given Malcolm et al.'s (2014) finding that they were rare and met infrequently. Such groups may provide siblings of children with CMN with a sense of belonging which they may not always experience at school due to the inherent differences between their own lives and those of their peers.

5.2.3.2 Aspects of School That Help and Hinder. All five superordinate themes related to the master theme, 'Aspects of School That Help and Hinder' were relevant to RQ3: 'The question of homework', 'Extra-curricular activities – time for me', 'The best parts of school for me', 'School rules and policies can help or hinder' and 'When I least enjoy school'.

5.2.3.2.1 The question of homework . Participants had varying experiences of homework, from those who found it reasonable, even when it coincided with increased responsibilities at home, to those who found it unmanageable, with consequences for not completing it deemed to be unfair. Even small amounts of homework presented a challenge for certain siblings of children with CMN, particularly given the interruptions by their ill sibling, their tiredness due to a lack of sleep, and lack of time as a result of additional caring responsibilities at home.

While the literature reviewed lacks any mention of the impact of homework on siblings of children with CMN, studies pertaining to the field of siblings of autistic children and young people have uncovered similar challenges to those faced by participants in the current study. One study found that such siblings found it difficult to complete homework when their autistic brother or sister was around, did not receive any help with homework from parents, and preferred to complete homework during school hours, where they could access support from peers or staff (Pavlopoulou et al., 2022).

Furthermore, the Sibs charity website contains advice to siblings of children with a variety of illnesses, disabilities and medical conditions about what they can do in response to a variety of challenges they may be experiencing related to school (‘School Life’, n.d.). This includes being unable to get homework done because of what is going on at home, being interrupted by their sibling have having caring responsibilities which means they do not have time (‘I Can’t Get Homework Done’, n.d.). The charity suggests well siblings might ask a parent to help them find a quiet space a home to do their homework, ask to do homework at a friend’s house or tell their teachers if their home circumstances are making it hard to complete (‘I Can’t Get Homework Done’, n.d.).

5.2.3.2.2 Extra-curricular activities – time for me. Extra-curricular activities played an important role in the lives of participants. Creative arts afforded siblings of children with CMN a means of self-expression. Participants lamented the fact that after-school clubs reduced the amount of time they were able to spend with their sibling with CMN. Nevertheless, they continued to attend them, implying the activities provided a vital space for them to develop their own sense of identity and interests. Financial cost could present a barrier to participation, with one sibling unable to continue art therapy for this reason, despite finding it helpful. While the literature review did not support these findings, Pavlopoulou et al. (2022) reported that siblings of autistic children benefitted from participation in extra-curricular activities, particularly those offered by their school. Such hobbies could bring enjoyment and pride, and increase their confidence (Pavlopoulou et al., 2022). However, a similar population studied by Barak-Levy (2010) were found to be much less likely than those without an autistic sibling to attend extra-curricular activities.

The literature also highlighted that siblings compartmentalised their school and home lives as a way of coping (Brennan et al., 2012; Grant & McNeilly, 2022; Nolbris et al., 2014). While the current study did not directly repeat this finding, it was notable that when asked if and how school life affected time with their sibling and vice versa, some participants struggled to think of ways in which the two interacted, and others spoke mainly about feeling tired at school because of being kept awake by their sibling, or the lack of time they had with their sibling as a result of school, homework and extra-curricular activities. Thus, without naming it as such, participants in the current research could be deemed to have compartmentalised their school and home lives to a certain degree.

5.2.3.2.3 The best parts of school for me. In the current study, siblings of children with CMN described having more positive experiences of primary school than of secondary school. This could be because of the sense of community at primary school, where everyone looked out for one another, or because teachers were perceived to have more realistic expectations and to care a lot more about them. Additionally, at secondary school, participants preferred schools that were small, where everyone was kind to each other, and where there was no bullying. Calm classrooms and a clear, gradual approach to teaching, so that pupils did not become overwhelmed, were also appreciated. School trips could be particularly memorable, and diversity was valued by siblings of children CMN, from schools which catered to pupils with a range of needs to those which served pupils from different ethnic and cultural backgrounds.

5.2.3.2.4 School rules and policies can help or hinder. School rules and policies could both help and hinder well siblings' experience of school. For instance, one participant who had moved secondary school found the zero-tolerance approach meant bullying was not tolerated at her new school. Mobile phone policies which required pupils to hand in their devices at the start of the day were preferred over rules prohibiting their use, which were not necessarily effective in preventing others accessing social media at school.

On the other hand, some rules were viewed as too strict and unfairly punitive for siblings of children with CMN. One participant explained that if she was late to school as a result of disrupted sleep, she would be issued with a detention, which, if not attended, would be escalated to a day in isolation. This was deemed illogical since the original misdemeanour was being late to lessons, and the punishment was to miss even more lessons.

5.2.3.2.5 When I least enjoy school. While most school-based experiences that well siblings recounted were positive, some participants had such poor experiences that they wanted to leave. Participants who did not enjoy attending a particular school tended to have a polarised view of it, finding it hard to think of anything good to say about it. Notably, this was contrasted with a glowing depiction of another school experience, whether it was their previous primary or new secondary school. This may reflect the fact that school is a place where siblings of children with CMN are usually able to experience some sort of normality (Brennan et al., 2012). Therefore, school may be seen as a form of respite or refuge and when it does not live up to expectations, it is bitterly disappointing and amplifies the challenges they face as the sibling of a child with CMN.

These insights into how siblings of children with CMN experience school – better experiences of primary than secondary school, preferences regarding the character of the school and teaching styles, the importance of school trips and of diversity in the student body, and the potential for rules to support siblings or exacerbate their issues – have not previously been illuminated in the literature.

5.2.3.3 Time for Change. The subtheme 'Times of transition can be challenging', from the master theme, 'Time for change', was relevant to RQ3.

5.2.3.3.1 Times of transition can be challenging. The transition from primary to secondary was a salient part of the school experience for certain participants, particularly those in lower year groups who had experienced it most recently. There was a sense that the anticipation of moving from primary to secondary school was worse than the reality. The transition was viewed as a 'big leap' for one well sibling, while another appreciated the measures the school took to ease pupils into their new routine and environment. While moving from primary to secondary school is an inevitable part of growing up for all young people, it appears to be a particularly anxiety-provoking time for siblings of children with CMN, who live with the constant threat of illness, caring responsibilities, disrupted sleep, challenges to participating in regular activities and so forth.

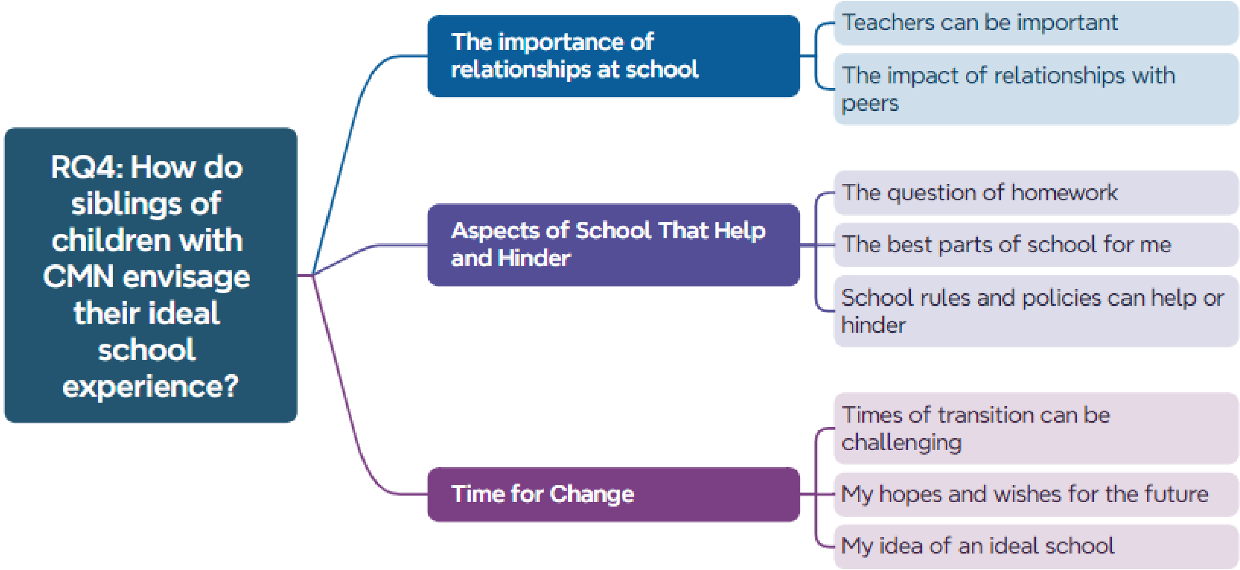
From an attachment perspective, it seems logical that well siblings should express sadness and fear about changing teacher at the end of the year, have a strong preference for the more nurturing approach of primary school teachers and struggle with the idea of moving to secondary school. Due to the limited time that they have with their parents because of the ill sibling's additional care needs, the unpredictability of their everyday lives and the precarious health and conduct of their sibling with CMN, teachers may represent even more significant attachment figures in the lives of well siblings than for the majority of their peers. Therefore, periods of transition at school may be especially worrisome and threaten the stability of the *secure base* represented by their primary school teachers.

5.2.4 RQ 4: How do siblings of children with CMN envisage their ideal school?

In order to garner responses to this research question, participants were asked to describe their ideal school. In addition to their responses to this question and follow-up ones, participants' answers to other questions throughout the semi-structured interviews were at times deemed relevant, both directly and indirectly contributing to the vision of an ideal school for siblings of children with CMN. For instance, when pupils spoke about the best parts of their current experience, it could be gleaned that these elements would also form part of their ideal school. Figure 5.4 sets out the master and superordinate themes deemed relevant to this research question. As much of this was covered in response to RQ2 and RQ3, only the superordinate theme, 'My idea of an ideal school', which has not yet been discussed, is explored here.

Figure 5.4

Master and superordinate themes from current study relevant to RQ4



5.2.4.1 Time for Change.

5.2.4.1.1 My idea of an ideal school. When asked to depict their ideal school, participants in the current study mostly spoke about a desire to improve relational aspects of their experience, reflecting their maturity, humility and pragmatism. Descriptions of bold rule changes, extravagant structural designs and fanciful features were conspicuous by their absence. Instead, siblings of children with CMN described their ideal school as one which met the needs of all pupils, with teachers who were considerate of their home circumstances and fellow pupils who were respectful and non-judgemental.

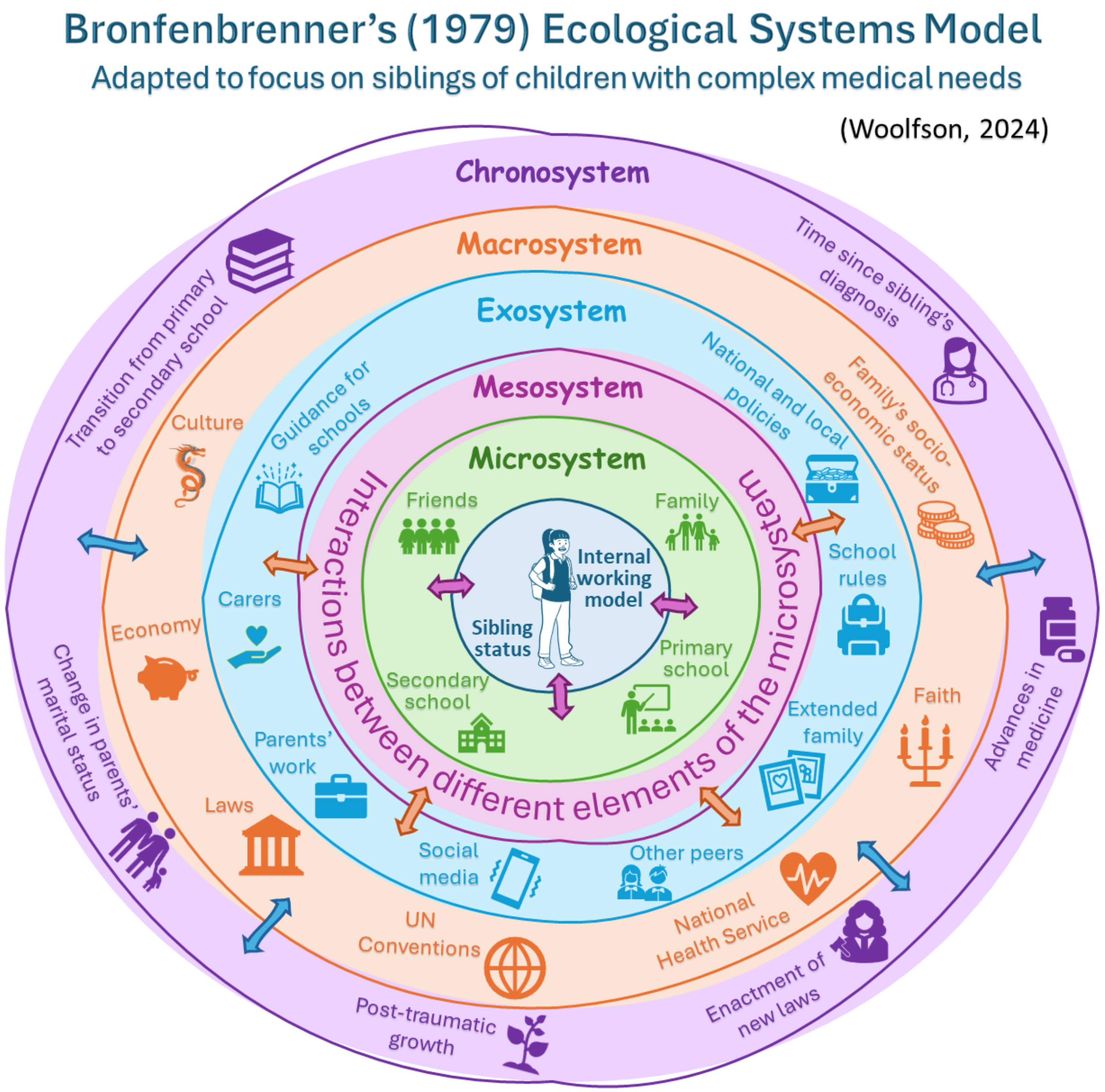
One participant wanted to change all of the people at her current school because they were not nice, and equated her ideal school with her primary school. The sole rule change mentioned was the ability to request an extension to homework deadlines without further questioning. Well siblings wanted teachers to ask them how they were and to be able to express when they were not alright, without being pressed for more information than they were willing to share. Above all, the ideal school for siblings of children with CMN was characterised by respect and understanding.

5.3 Siblings of children with CMN: an ecological systems model

To convey the findings of the current study succinctly to a range of audiences, the factors found to affect siblings of children with CMN in previous literature and the current study were depicted graphically using Bronfenbrenner's (1979) ecological systems model as a framework (see Figure 5.6). The illustration helps to reinforce the idea that siblings of children with CMN are not one homogenous entity, but rather, that their experiences are shaped by the interplay of multifaceted layers of influence. An understanding of well siblings' experiences through this lens may allow schools and EPs to better target support for siblings with CMN by recognising the complex, interacting factors that affect their development, and the various potential avenues that can be targeted to elicit growth and positive change.

Figure 5.5

Siblings of children with CMN: an ecological systems model



5.4 Limitations of findings

Several limitations exist in relation to participant characteristics, recruitment, data collection methods and type of analysis employed in the study.

Notably, the term *children with CMN* is somewhat broad and imprecise. Even though parents of participants and the researcher agreed that the ill siblings met the definition set out in the introductory chapter, their needs varied drastically, from those who were able to be left at home alone and attend mainstream schools, to those who required round-the-clock supervision and care and a highly specialist educational setting. This may account for some of the differences between participants' experiences.

While the age range of participants was relatively small (11-15 years old), the sample represented a broad variation in developmental level, with some participants having recently started secondary school and others in their final year of GCSEs. As a result, participants differed in level of maturity and overriding concerns. Furthermore, only one of the six participants was male, and only one of the participant's siblings with CMN was male, so it was not possible to examine the effect of gender on participants' experiences, and the experiences may be skewed towards a female perspective. All of the participants were older than their siblings with complex medical needs. Therefore, any differences in the experiences of younger siblings may not be fully represented in the data. Although demographic information relating to ethnicity, religion and country of origin was not collected, all participants in the study appeared to be white British and to speak English as a first language. As a result, the views expressed may not be entirely representative of those from different ethnic and cultural backgrounds. Therefore, there may be aspects of their experience missing from participants' narratives, such as the focus on faith found in narratives of children in Haiti by McPoland et al. (2017).

Semi-structured interviews with individual participants were deemed to be the most appropriate method of data collection for this study. Nevertheless, the use of focus groups may have been more effective in allowing the researcher to access knowledge and attitudes that can emerge from everyday forms of communication, such as jokes and anecdotes, which may not be accessed through reasoned responses to interview questions (Kitzinger, 1995). Furthermore, recruitment for focus groups may have encouraged the participation of some who would not have put themselves forward for individual interview. Nevertheless, it is also recognised that those who were willing to participate in individual interviews may not have been comfortable with a focus group format.

The fundamental drawbacks of IPA as an analytical approach have been well documented (see, for example, Brocki & Wearden, 2006; Hefferon & Gil-Rodriguez, 2011; Tuffour, 2017). Nevertheless, there are a few issues worth highlighting in the context of the current study. IPA is essentially a subjective approach and therefore each analyst is likely to interpret the data differently (Tuffour, 2017). However, this is arguably true of all qualitative methods of analysis to a greater or lesser extent, and by actively acknowledging the subjectivity of the researcher, IPA incorporates a greater degree of transparency than some other qualitative approaches.

Another potential criticism of IPA generally, and the current study in particular, is the lack of control group (Hefferon & Gil-Rodriguez, 2011). The current study involved conducting and analysing semi-structured interviews with siblings of children with CMN. Their responses were not subsequently compared and contrasted with those of young people without a sibling with CMN. Thus, it is at times unclear which findings can be attributed exclusively to siblings of children with CMN, and which may be more widely applicable to young people today.

5.5 Implications for schools

One of the key issues for siblings of children with CMN is that they do not necessarily constitute an identifiable group and schools may be unaware of their individual home circumstances. This is particularly true when well siblings reach secondary school and are taught by several teachers in a single day. During the admission process, schools may wish to ask parents whether the pupil has a sibling (or other family member) with a disability or illness, as recommended by Sibs (‘Recommendations for Schools’, n.d.). However, not all well siblings want their sibling status to be shared with their teachers, and this is a decision for them and their parents to make. In the case that this information is not shared, there are certain steps schools can take to cater to the needs of siblings of children with CMN, which will simultaneously benefit all pupils, particularly those with hidden challenges. These include:

- Being kind. All teachers, teaching assistants and non-teaching staff in schools should always be expected to treat all pupils with empathy, kindness and understanding, regardless of their background, needs or behaviour.
- Setting homework well in advance of the deadline to give pupils plenty of time to complete it.
- Considering requests for an extension to homework deadlines on a case-by-case basis.
- Ensuring homework is set at a level accessible to the individual; not all pupils, including siblings of children with CMN, have a parent/carer on hand to help them.
- If pupils are late to school, asking why they are late and listening to their reason. If they say it was a result of disrupted sleep or helping with a sibling, it may be helpful

to contact the parent to get a better understanding of the circumstances. It may be best for a member of the pastoral team to decide whether a detention, other sanction or no sanction is most appropriate.

- Having a zero-tolerance approach to bullying, including the use of discriminatory or degrading language.
- Providing a range of extra-curricular activities before, during and/or after school to enable children and young people to develop their own interests.

Where a school is aware that a pupil is the sibling of a child with CMN, it should:

- Consider the impact of rules and policies on them, and whether adaptations need to be made in light of their circumstances, particularly during sensitive periods, for example, if the child with CMN is in hospital.
- Allocate a key person/mentor with whom they can check in at least on a weekly basis.
- Where possible, run a discussion-based support group for siblings of children with CMN and/or disabilities where well siblings can share their experiences with other young people with similar home circumstances.
- Provide additional support to siblings of children with CMN during times of transition, e.g. transition between year groups in primary school and between primary and secondary school. These can be difficult for well siblings and additional time to adjust to the changes will be reassuring and comforting.

- Avoid making judgements and comparisons between siblings of children with CMN and other pupils/people. Well siblings and their circumstances are unique and extraordinary; they should be treated as such.

5.6 Implications for EP practice

EPs are in a unique position to help identify and raise the profile of siblings of children with CMN. During involvement with a child or young person with CMN, the EP can ask whether parents/carers have informed their other children's school (if different from that of the child being assessed) that they have a sibling with CMN. If not, the EP can recommend that they do so to enable the school can take additional steps to ensure their needs are met. EPs can also:

- Work systemically with schools to support staff to think about how they might identify and support siblings of children with CMN within the context of their school.
- Run training sessions for school staff on how to support siblings of children with CMN.
- Use interprofessional working opportunities to raise awareness of the needs of well siblings among healthcare professionals to enable them to incorporate consideration about siblings' needs into the care provided to a child's family at the point of diagnosis of CMN.
- Run or help to run workshops for parents of children with CMN in which they consider the needs of the siblings and the appropriate type and level of communication with siblings about their brother or sister's condition.
- Help to set up and/or run sibling support groups with pupils from one or more schools.

- Work directly with siblings of children with CMN to gain their views or train staff to use person-centred planning tools to enable them to do so.
- Signpost schools and/or families of children with CMN to websites and organisations which provide information and support for siblings of children with CMN.

5.7 Implications for future research

It would be useful to conduct longitudinal research exploring changes in the experiences of siblings of children with CMN over time. This would allow researchers to understand how the siblings' experiences and relationships evolve as they grow up and mature, and as different stressors and challenges come to the fore.

One of the findings of the current study was that well siblings reported more positive experiences of primary school than of secondary school. It would be helpful to investigate further the elements of primary school that are particularly appreciated by well siblings so that secondary schools can harness this learning and attempt to replicate certain elements of primary school settings to better cater to siblings of children with CMN.

While a variety of methods to recruit participants was employed, all participants in the current study were ultimately recruited through their parents on groups aimed at families of children with specific conditions on social media. It is possible that those who seek out such groups on social media represent a specific subsection of the target population, and may not be representative of the population as a whole (Andrews, 2012). Therefore, it may be helpful to undertake further research with participants recruited via other means in order to gain a broader understanding of the experiences of siblings with CMN.

Future research may also seek to address the limitations of the current study, for example, by recruiting a range of well siblings who are both younger and older than their sibling with CMN, by ensuring a more even split between male and female participants, by including siblings from a range of ethnic and cultural backgrounds, and by employing a focus group method to elicit responses.

5.8 Plans for dissemination

The remaining sections will be written in first person to reflect the personal nature of them.

I intend to create a shortened, accessible summary of the research findings and their implications to send to the parents of all participants. This was offered at the recruitment stage and all parents indicated they would like to receive this. I will also share this summary with others who expressed an interest in my findings during the recruitment phase, including the Chief Executive Officer of The Maypole Project and members of groups on social media where the study was advertised, as well as with other relevant organisations.

I plan to present my research findings at a team meeting in my local Educational Psychology Service during a Continuous Professional Development session, as well as to my fellow students and tutors at the UEL Research Day in July 2024. I will also share the research findings and implications with the SEND team in the local authority in which I work so that it can be shared with schools via the SENCO newsletter. Furthermore, a copy of this thesis will be made available electronically via the UEL repository and the on the British Library's EThOS website. Lastly, I hope to publish an article based on the current study in an academic journal.

5.9 Reflections on the research process

When I set out on my research journey, I expected the recruitment of participants to be relatively straightforward given my previous involvement with The Maypole Project. In reality, recruitment turned out to be one of the greatest challenges of completing this thesis. At several points, I was tempted to find an alternative topic that would involve recruiting from a much wider or more easily accessible pool. Nevertheless, my perseverance paid off, and I am extremely grateful to have been able to interview siblings of children with CMN directly about their experiences.

Although nerve-wracking at first, I found the interview process immensely rewarding. On a few occasions during the interviews, I caught myself having thoughts that were more aligned with those of a TEP or even in one of my roles prior to commencing the Doctorate. For instance, I instinctively wanted to share my own experience of having been a SENCo with a participant who shared her ambitions to become one. Nevertheless, in that moment, I became acutely aware of my role as researcher and how sharing this information could potentially affect the rapport I had built with her, and her willingness to continue being open about her experiences, particularly given her negative interactions with teachers generally, including her brother's SENCo. In order to remain as objective as possible, I consciously decided to withhold such information, and reflected it on it subsequently in my reflective journal.

Throughout the interviews, I remained self-aware of my own reactions to the information shared by participants. For instance, I was shocked and deeply saddened when one participant spoke about caring for her sibling with CMN who became “floppy” while she was changing him. However, realising that it would not be appropriate to show or share how I was feeling given the interview situation, I paused, took a deep breath, and continued to listen to the participant and ask relevant questions. While it was important to empathise with participants, it would not have been helpful to show my own emotional reactions, particularly to experiences which for them are part of their everyday lives. My role as a researcher was to listen, not to judge or react to what they were telling me. Instead, I used my reflective journal and supervision with my Director of Studies to help me process my emotions and relieve any strong feelings that arose in me during the interviews.

The use of semi-structured interviews meant that I had to make split-second decisions about what to ask next, how gently or otherwise to steer the conversation in a certain direction, and whether to reiterate questions if I did not feel they had been answered. For example, when I asked participants how they would describe their ideal school, several of them spoke about inclusive schools which met the needs of pupils like their siblings, whereas my question was intended to elicit what elements of a school were most important for their own learning and wellbeing. However, when I reflected on this after the interviews, I realised that participants were saying that inclusive schools which catered to the needs of all children *was* what they believed to be best for their own learning and wellbeing, not just for their sibling's.

When it came to the writing process, I went through peaks and troughs; I loved and loathed it in equal measures. It felt incredible to receive feedback from one participant after sharing a summary of my findings that I had "just got it" (personal communication, 17/03/2024); it was drudgery while the rest of the country went on holiday to far flung destinations and I had to stay at home to write. Nevertheless, I powered through, inspired by the siblings of children with CMN who had given up what little free time they had to share their stories with me in the hope of making a difference for those who would be thrust into their position in years to come. I also learnt what worked best for me along the way: planning how I would use my time, including when to take breaks; remembering that the best laid plans *gang aft agley*; asking for help when I needed it; being selective about whether or not to take on board other people's advice; remembering it was not the end of the world if I did not complete it on time; reminding myself that if it I did not complete it on time, I would likely be staying at home while the rest of the country went on holiday this summer.

5.10 Conclusion

The current study explored the lived experiences of siblings of children with CMN and identified ways in which schools and EP could support them. The findings largely supported those of earlier research, highlighting well siblings' appreciation of family, the difficulties they encounter doing everyday activities, their additional responsibilities, disruptions to their sleep, the problem with homework and the lack of understanding from peers. It also revealed novel findings, such as the impact of certain rules and policies on their school experience, the fact that well siblings tended to have a better experience of primary than secondary school, their appreciation of diversity and their conception of an ideal school.

The findings from the literature and the current study led to a visual depiction of the lived experiences of siblings of children with CMN using the ecological systems model as a framework, which could be used to help educational professionals grasp the complex web of interacting factors affecting well siblings' development and to identify how to target support most effectively. The findings also led to recommendations as to how schools and EPs can support siblings of children with CMN. Schools may not be aware of a pupil's sibling status, yet there are steps that can be taken to help meet the needs of siblings of children with CMN, simultaneously benefitting all pupils. Above all, siblings of children with CMN want and deserve kindness. As the Dalai Lama is often quoted as saying, “Be kind whenever possible. It is always possible.” Never have these words rung truer.

Given the aims of the research, it seems fitting that the final words should go to one of its participants, who beautifully summed up her experience as the sibling of a child with CMN: “I would never change my life but there will always be moments I find it hard and overwhelming and also moments I think I’m the luckiest sister to be blessed with someone so special as her.”

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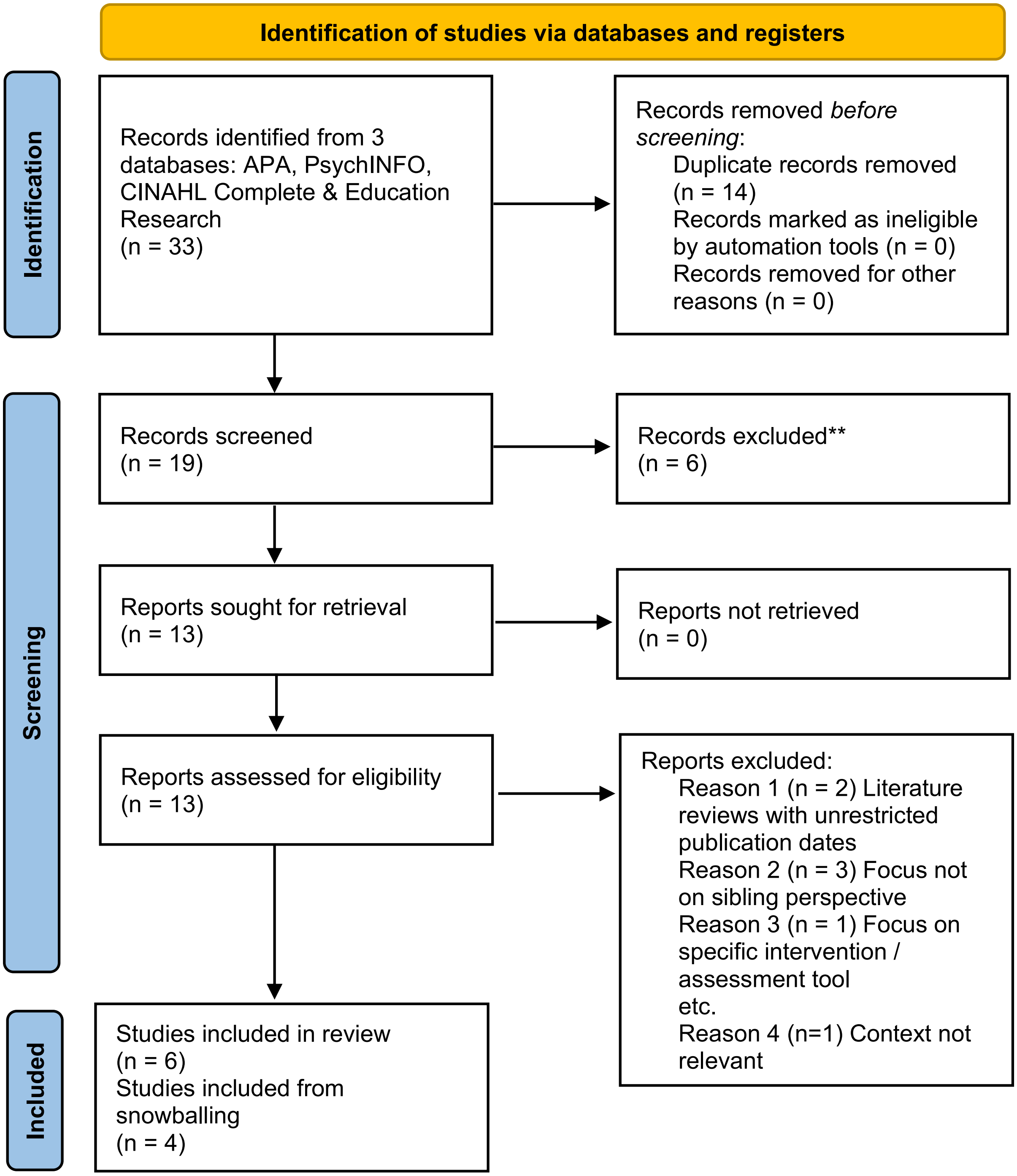
Appendix A.

PRISMA Diagram for Systematic Review of the Literature



Appendix B.

Review of Articles Using the Mixed Methods Appraisal Tool

1. Malcom et al., 2014

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			What are the sibling experiences of children with rare and progressive life-limiting conditions?
	S2. Do the collected data allow to address research questions?	X			Daily symptom diary and interviews with siblings
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Grounded theory used to analyse data from interviews
	1.2 Are the qualitative data collection methods adequate to address the research question?	X			Interviews including a card sort activity to engage and help thicken description of experiences
	1.3 Are the findings adequately derived from the data?	X			Four key themes derived from the data: Perception of the condition and its symptoms; Impact of the condition on family life; Emotional responses from siblings; and Coping and support
	1.4 Is the interpretation of results sufficiently substantiated by data?	X			Relevant quotes used to back up findings
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			Authors give clear rationale for using interviews with card sort and use of grounded theory to analyse and interpret data

2. Jaaniste, Cugansen, et al., 2022

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	**No**	**Can't tell**	**Comments**
Screening questions (for all types)	S1. Are there clear research questions?	X			What is the self-reported psychosocial functioning (namely the psychological, social and school functioning) of well siblings who have a brother or sister with an LLC? What is the level of agreement between well sibling self-reported functioning and parent proxy-reports of well sibling functioning.
	S2. Do the collected data allow to address research questions?	X			Paediatric Quality of Life Inventory used – a self-report and parent-proxy questionnaire designed to assess the key domains of paediatric physical, emotional, social and school functioning.
Quantitative descriptive	4.1 Is the sampling strategy relevant to address the research question?	X			Participants are parents and well siblings aged 6 years + in a family with a child with an LLC known to the palliative care services in Sydney, Australia
	4.2 Is the sample representative of the target population?	X			Study of 48 siblings and 42 parents from 32 families
	4.3 Are the measurements appropriate?	X			Self-report and parent-proxy questionnaire from the Pediatric Quality of Life Inventory (PedsQL; Varni et al., 2001) employed to assess of emotional, social and school functioning

	4.4 Is the risk of nonresponse bias low?	X			Exclusion criteria includes families where a child had received a diagnosis of an LLC less than 1 month ago or if the child was believed to be in the terminal phase and close to death
	4.5 Is the statistical analysis appropriate to answer the research question?	X			One-sample T tests used to compare different domains of psychosocial functioning of sibling and parents with population norms; Pearson correlation carried out to examine associations between measures of resilience and functioning between parents' and self-report.

3. Brennan et al., 2013

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			What are the experiences of siblings of children with life-limiting conditions and how do they cope with those experiences?
	S2. Do the collected data allow to address research questions?	X			A qualitatively driven, longitudinal, mixed-method approach, whereby the quantitative measures established a context for interpreting and validating aspects of the qualitative data (Moran-Ellis et al., 2006)
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			
	1.2 Are the qualitative data collection methods adequate to address the research question?				
	1.3 Are the findings adequately derived from the data?				
	1.4 Is the interpretation of results sufficiently substantiated by data?				
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
2. Quantitative randomized controlled trials	2.1 Is randomization appropriately performed?				
	2.2 Are the groups comparable at baseline?				
	2.3 Are there complete outcome data?				
	2.4 Are outcome assessors blinded to the intervention provided?				

	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1 Are the participants representative of the target population?				
	3.2 Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3 Are there complete outcome data?				
	3.4 Are the confounders accounted for in the design and analysis?				
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1 Is the sampling strategy relevant to address the research question?	X			
	4.2 Is the sample representative of the target population?				
	4.3 Are the measurements appropriate?				
	4.4 Is the risk of nonresponse bias low?				
	4.5 Is the statistical analysis appropriate to answer the research question?	X			
5. Mixed methods	5.1 Is there an adequate rationale for using a mixed methods design to address the research question?	X			Quantitative measures establish a context for interpreting and validating aspects of the qualitative data
	5.2 Are the different components of the study effectively integrated to answer the research question?	X			Strengths and Difficulties Questionnaire (SDQ; (Goodman, 1997)),Harter Self-Perception Profile (SPP; Harter, 1985b) and Kidcope (Spirito et al., 1998) completed at each visit (one per year over three years); photo-elicitation and button task used to facilitate

					narrative discussion on sibling experiences at visit 2; semi-structured interview at visit 3
	5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			Results of standardised measures used to contextualise interview data and integrated into the qualitative analysis to inform the model of sibling adaptation;
	5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			Data from interviews contrasted with findings of standardised measures (e.g. results from Kidcope reflect a heavier reliance on avoidant strategies compared to compartmentalisation strategy derived from interview)
	5.5 Do the different components of the study adhere to the quality criteria?	X			Participatory research methods used; grounded theory approach to analyse semi-structured interviews; integration of results of standardised measures in analysis of interview data

4. Jaaniste, Chin, et al., 2022

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			How do the parents and siblings of children with a life-limiting condition communicate? What are the predictors of the amount of communication between them?
	S2. Do the collected data allow to address research questions?	X			Questionnaires administered to parents and well siblings and analysed using SPSS v26
Quantitative descriptive	4.1 Is the sampling strategy relevant to address the research question?	X			Participants were well siblings aged 6 years + with a brother or sister with a LLC known to pediatric palliative care at various hospitals in Sydney, Australia.
	4.2 Is the sample representative of the target population?	X			Participants were 48 sibling-parent dyads from 32 families
	4.3 Are the measurements appropriate?	X			Measures were the Parent-Sibling Communication Measure (COMSIB; Cohen et al., 1989) originally developed for parents and siblings of children with cancer; the Family Communication Scale (FCS; Olson et al., 2004); the Family Environment Scale (FES; Holihan & Moos, 1983; Moos & Moos, 2009); the Pediatric Quality of Life Inventory (Peds-QL; Varni et al., 2001); the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond,

					1995); and the Child/Youth Resilience Measure (CYRM-12; Liebenberg et al., 2013)
	4.4 Is the risk of nonresponse bias low?	X			Of the 46 eligible families, 32 participated in the study. Reasons stated for not participating were limited time, practical difficulties and concern for wellbeing of the well sibling.
	4.5 Is the statistical analysis appropriate to answer the research question?	X			Analysis included descriptive statistics, chi-squared tests, multiple regression analyses and t-tests to explore the relationship between communication between the well sibling and their parents and variables such as parental resilience, age of well siblings, gender, time since diagnosis and satisfaction with level of communication.

5. McPoland et al., 2017 (Poster Abstract only)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	**No**	**Can't tell**	**Comments**
Screening questions (for all types)	S1. Are there clear research questions?	X			What are the differences in understanding of death and dying among children from diverse cultural backgrounds?
	S2. Do the collected data allow to address research questions?	X			Semi-structured interviews with patients with life-threatening illnesses and their siblings aged 5-18 years about illness experience, understanding of death and dying, and coping
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Semi-structured interviews to explore sibling's experiences and understanding
	1.2 Are the qualitative data collection methods adequate to address the research question?			X	Article does not detail the number of children interviewed
	1.3 Are the findings adequately derived from the data?			X	No quotes included in the article meaning it is not possible to tell whether findings are adequately derived from the data
	1.4 Is the interpretation of results sufficiently substantiated by data?			X	No raw data presented
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?			X	As above

6. Grant & McNeilly, 2022

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	**No**	**Can't tell**	**Comments**
Screening questions (for all types)	S1. Are there clear research questions?	X			What are children and young people's experiences of having a sibling with complex health needs?
	S2. Do the collected data allow to address research questions?	X			Literature review including nine studies relevant to research question
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Literature review of studies examining the research question using parental reports and sibling self-reports
	1.2 Are the qualitative data collection methods adequate to address the research question?	X			Thematic synthesis used to group findings and identify main themes
	1.3 Are the findings adequately derived from the data?	X			Findings are presented thematically with references to specific pieces of research from literature review and some quotes
	1.4 Is the interpretation of results sufficiently substantiated by data?	X			Findings of research substantiated by evidence and contrasting evidence presented
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			Positives and negatives of being a sibling of a child with complex health needs presented; limited resources to aid parents to talk to their children about siblings with complex health needs

7. Haukeland et al., 2015

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	**No**	**Can't tell**	**Comments**
Screening questions (for all types)	S1. Are there clear research questions?	X			What are the emotional experiences of siblings of children with rare disorders?
	S2. Do the collected data allow to address research questions?	X			Qualitative thematic analysis conducted based on videotapes of 11 support groups for 58 siblings aged 7-17 years
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Support groups for siblings of children with rare disorders in a naturalistic setting
	1.2 Are the qualitative data collection methods adequate to address the research question?	X			Data based on video recordings of 20 regular group sessions with 11 different support groups
	1.3 Are the findings adequately derived from the data?	X			Meaningful units in which participants described their subjective experience selected from video-tapes and transcribed; principles of thematic analysis applied to transcripts with subsequent coding in inductive manner; consensus coding applied.
	1.4 Is the interpretation of results sufficiently substantiated by data?	X			Quotes used to back up analysis
	1.5 Is there coherence between qualitative data sources,	X			Emotional experiences described by siblings

	collection, analysis and interpretation?				categorised into three main dimensions and explored through thematic analysis with quotes included from group sessions

8. Nolbris et al., 2014

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			How do siblings' describe their thoughts about grief related to the experience of having a brother or sister with cancer?
	S2. Do the collected data allow to address research questions?	X			Open-ended interviews with 29 siblings of a child with cancer, aged 9 to 24 years old
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Interview questions allow participants to talk openly about experiences
	1.2 Are the qualitative data collection methods adequate to address the research question?	X			Direct report of experiences by siblings themselves
	1.3 Are the findings adequately derived from the data?	X			Findings clearly delineated under four major themes
	1.4 Is the interpretation of results sufficiently substantiated by data?	X			Quotes used to back up analysis
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			Four types of grief derived from interviews: anticipatory grief; grief at having been deprived of a 'normal' childhood; feeling forgotten or unimportant in the family; and grief if/when the sibling died
	5.5 Do the different components of the study adhere to the quality criteria				

9. Gaab et al., 2014

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	**No**	**Can't tell**	**Comments**
Screening questions (for all types)	S1. Are there clear research questions?	X			What are the concerns of siblings of pediatric palliative care (PPC) patients?
	S2. Do the collected data allow to address research questions?	X			Qualitative semi-structured interviews with 18 young people aged 9 to 22 years who had a sibling receiving PPC or who had received PPC prior to their death
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Semi-structured interviews with siblings about their own experiences
	1.2 Are the qualitative data collection methods adequate to address the research question?	X			Interviews with 18 young people aged 9 to 22 years from a total of 9 families who had the cognitive ability to verbalise their perspectives
	1.3 Are the findings adequately derived from the data?	X			Interviews transcribed and analysed as a complete collection, discounting differences between bereaved and nonbereaved siblings using Braun and Clarke's method of inductive thematic analysis
	1.4 Is the interpretation of results sufficiently substantiated by data?	X			Extensive quotes used to illustrate themes. Two most robust themes analysed: participants knowledge about

					death and involvement in the care of siblings.
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			Themes of helping and mortality explored with quotes from interviews. Suggestions made as to how to best support siblings based on their self-reported experiences as the sibling of a child receiving PPC.

10. Løkkeberg et al., 2020

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	**No**	**Can't tell**	**Comments**
Screening questions (for all types)	S1. Are there clear research questions?	X			What are the experiences of adolescents with a sibling suffering from cancer from a salutogenic health promotion perspective?
	S2. Do the collected data allow to address research questions?	X			Interviews with seven siblings analysed using qualitative content analysis
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	X			Open-ended questions to obtain adolescents' experiences; analysis method facilitates understanding the text in different abstraction and interpretation levels
	1.2 Are the qualitative data collection methods adequate to address the research question?	X			Semi-structured interviews with 7 siblings of children with a cancer diagnosis
	1.3 Are the findings adequately derived from the data?	X			Meaning units identified and condensed; condensed meaning unit coded and sorted into subcategories and categories representing the manifest content; categories led to a mean theme, representing the latent content which was interpreted and discussed by the authors

	1.4 Is the interpretation of results sufficiently substantiated by data?	X			Quotes provided to illustrate themes
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			Authors present evidence of credibility, transferability, dependability and confirmability – the four criteria set out by Lincoln and Gubba (1985) to enhance trustworthiness in qualitative research

Appendix C.

Findings From the Literature Review

Codes:

1. Negative emotions experienced
2. Challenges of having a sibling with CMN
3. Positive aspects of having a sibling with CMN
4. Communication with others
5. Unmet needs of siblings
6. Coping mechanisms/support
7. Responsibility / maturity
8. Compartmentalising
9. Changes to 'the norm'
10. Discrepancy between parent and child views
11. Gender/cultural differences
12. Individual preferences
13. Familial cohesion
14. Knowledge about sibling's illness
15. School factors
16. Friendships
17. Bond with siblings
18. Identity
19. Difference in parents
20. The future
21. **Differential treatment of sibling**

Article Title & Author(s)	**Methods**	**Findings**
A relational understanding of sibling experiences of children with rare life-limiting conditions: Findings from a qualitative study.	Daily symptom diary and semi-structured interviews; card sort to thicken descriptions; 8 siblings interviewed	Challenges faced by siblings in assessing brother or sister's symptoms, "can't exactly tell if he's feeling sore" (p.5); (Malcolm et al., 2014) worry about whether symptoms indicate imminent death'; (Malcolm et al., 2014) coping with changes in siblings' presentation; (Malcolm et al., 2014) siblings know more about condition than parents think they do; (Malcolm et al., 2014)

(Malcolm et al., 2014)		siblings take pride in the care their family undertook; (Malcolm et al., 2014) sense of sibling supporting others to care rather than taking full responsibility; (Malcolm et al., 2014) limitations put on family/social life as a result of ill child's illness; (Malcolm et al., 2014) worry pervades siblings' lives, including difficulties concentrating at school and social time with friends; (Malcolm et al., 2014) anxiety increases when siblings' health deteriorates; (Malcolm et al., 2014) siblings aware of how worrying feelings can reverberate around the wider family system; (Malcolm et al., 2014) two siblings teased by peers because of siblings' condition – lack of timely intervention by adults; (Malcolm et al., 2014) experience of negative attitudes in the community; (Malcolm et al., 2014) wish for people to be more accepting; (Malcolm et al., 2014) siblings are protective and do not understand why people can be so unkind; (Malcolm et al., 2014) empathy towards sibling (Malcolm et al., 2014) some siblings unable to say where they get support from or how they cope with long-term impact of ill sibling's illness; (Malcolm et al., 2014) one sibling talked of sense of isolation; (Malcolm et al., 2014) organised sibling support groups valued and enjoyed, but infrequent meetings; (Malcolm et al., 2014) some talked about keeping in touch with other siblings via e-mail or text; (Malcolm et al., 2014)

		understanding and acceptance important qualities in friends; (Malcolm et al., 2014) main sources of support are family members and friends; (Malcolm et al., 2014) worry and anxiety pervades many aspects of siblings' lives; (Malcolm et al., 2014) data suggest that support for siblings' should take into account the trajectory of the illness and the family, school and peer relational contexts that siblings inhabit; (Malcolm et al., 2014) Siblings may not communicate their worries for fear of adding to parental burden. (Malcolm et al., 2014) Limitations: small sample size; theoretical sampling traditionally used in grounded theory was not possible due to small number of children affected by rare life-limiting conditions; card sort had limited use – most data gleaned from verbal responses.
Children and young people's experiences of having a sibling with complex health needs: a literature review. (Grant & McNeilly, 2022)	Literature review	Ill health of a sibling affected emotional state of other children in family; (Grant & McNeilly, 2022) Well sibling experienced mixed emotions including jealousy, embarrassment, sadness, happiness and frustration; (Grant & McNeilly, 2022) When condition of ill sibling deteriorates, impact felt throughout family; (Grant & McNeilly, 2022) Siblings of children with life-limiting conditions had comparable heightened emotional and behavioural difficulties to siblings of autistic children in a matched comparison group; (Grant & McNeilly, 2022) As siblings get older, their emotional and behavioural issues are heightened as their understanding and coping abilities change; (Grant & McNeilly, 2022) Some sought refuge in activities outside the home, e.g. school, music, sport and support groups; (Grant & McNeilly, 2022)

		Others found comfort in speaking to a close friend or family member ; (Grant & McNeilly, 2022) Comfort in being involved in caring for sibling (Grant & McNeilly, 2022) Active and passive coping strategies – active included; (Grant & McNeilly, 2022) Siblings rely on distraction from home situation and actively avoid social situations that may cause people to stare; (Grant & McNeilly, 2022) Many siblings compartmentalised their lives and did not mix life inside the home with life outside the home, so friends often unaware of ill sibling; (Grant & McNeilly, 2022) Communication from family and awareness of condition important to siblings; (Grant & McNeilly, 2022) Support groups rare but useful as safe space to talk; (Grant & McNeilly, 2022) Feelings of guilt at needing parents to travel far with them to support groups; (Grant & McNeilly, 2022) Desire to belong to a group in which home situation was understood and where they could feel 'normal'; (Grant & McNeilly, 2022) Some siblings prefer talking to peers than adults while others felt more mature than peers and felt adults understood them better; (Grant & McNeilly, 2022) Siblings associated improvements in ill child's health with less chaotic family life; (Grant & McNeilly, 2022) Some incorporated ongoing treatment routines into 'normal' family life; (Grant & McNeilly, 2022) Others felt their life was 'on hold' when sibling's illness deteriorated; (Grant & McNeilly, 2022)

		Siblings used to last minute changes and cancellation of extracurricular activities because of ill child's needs (Grant & McNeilly, 2022) Some felt frustrated that they could not make plans and other resentment that they were missing out on family life. Jealousy and sadness at feeling less important to their parents than ill child. (Grant & McNeilly, 2022) Positive aspects: feeling a sense of accomplishment when talking about activities completed together as a family (Grant & McNeilly, 2022)
Living with a child who has a life-limiting condition: The functioning of well-siblings and parents. (Jaaniste et al., 2022)	Participants: 48 siblings and 42 parents of children with life-limiting conditions; Pediatric Quality of Life Inventory (PedsQL; Varni et al., 2001) – self-report and parent-proxy questionnaire assessing emotional, social and school functioning; Child/Youth Resilience Measure (CYRM-12; Liebenberg et al., 2013) – a 12-item self report measure assessing resilience processes in children/youth;	Siblings of children with LLC self-reported significantly poorer emotional, social and school functioning compared with published norms for school children. (Jaaniste et al., 2022) Fewer siblings affirmed that they were able to fix things when they didn't go their way (63.8%) without hurting themselves or others relative to parents (97.6%). (Jaaniste et al., 2022) Siblings (and parents) both more likely to report that family cares about them when times are hard than that their friends care about them. (Jaaniste et al., 2022) Sibling resilience positively correlated with emotional, social and school functioning. Results point to importance of holistic, family-centred palliative care, which addresses the unique needs of well siblings. (Jaaniste et al., 2022) Poor agreement between parental perceptions of sibling functioning and self-report for all domains of functioning. (Jaaniste et al., 2022)

	participant well siblings aged 6 to 21 years (mean = 11.7, SD = 4.1)	
Paediatric life-limiting conditions: Coping and adjustment in siblings. (Brennan et al., 2012)	Qualitatively driven longitudinal mixed methods study of 31 siblings aged 5 to 16 seeking to answer 'what are the experiences of siblings of children with life-limiting conditions and how do they cope with those experiences?'.	Participants showed high feelings of self-worth with 70% scoring above the norm on the SPP – Harter Self-Perception Profile (Harter, 1985b). (Brennan et al., 2012) Results from self-report SDQ indicated that siblings' emotional and behavioural symptoms were within the 'normal' range on all scales. (Brennan et al., 2012) Three key themes: *compartmentalising life, position in the adult world* and *self as glue in relationships* which represent forms of coping and adaptation. (Brennan et al., 2012) Siblings saw their childhood as a substantive departure from normality, which engendered feelings of difference and standing out (Brennan et al., 2013) Siblings seek and enjoy compartmentalisation between home and school (Brennan et al., 2012) Siblings determined to live in present and avoid rumination about the past and future (Brennan et al., 2012) Kidcope results reflect heavier reliance on avoidant strategies with distraction, wishful thinking, resignation and social withdrawal being the most common coping strategies reported (Brennan et al., 2012) Siblings characterised themselves as caring and loving and reported caring duties (e.g. as a companion to sibling, feeding, bathing, dressing or toileting); (Brennan et al., 2012) Siblings actively avoid arguments with friends and act as peacemaker if a dispute arises, either at home or school. (Brennan et al., 2012)

		Perception of themselves as glue was often coupled with sense of responsibility, even for events outside of control. (Brennan et al., 2012) Siblings had sense of needing to be emotionally self-sufficient. (Brennan et al., 2012) Siblings reported deprioritising their own needs to accommodate others and often silenced their own emotions (Brennan et al., 2012) Caring responsibilities meant siblings had to forgo other activities; (Brennan et al., 2012) Majority viewed their responsibility positively. (Brennan et al., 2012) Many sought responsibilities – aligning themselves with adults, e.g. taking responsibility for decisions. (Brennan et al., 2012) Sense of purpose and self-worth from caring responsibilities. (Brennan et al., 2012) Compartmentalisation may be an avoidant coping strategy. Such strategies are associated with a high level of distress in response to stress (O'Connor & O'Connor, 2003) and risk factor for anxiety and depression in adolescents (Gomez & McLaren, 2006). (Brennan et al., 2012) Findings suggest that siblings may negate their own needs, preferring to be a caregiver rather than caretaker. (Brennan et al., 2012) They reported often lacking parental attention and as being unable to forge a 'normal' sibling relationship with their brother or sister. (Brennan et al., 2012) Limitations: may not be representative; those who participated may be coping well with situation; diversity of sample across several variables limits wider interpretation of themes, e.g. wide age range spans different developmental stages; no comparison group;

Parent and Well sibling Communication in Families With a Child Who Has a Life-Limiting Condition: Quantitative Survey Data Jaaniste et al., 2021b	Parents and well siblings independently completed validated measures of familial communication and sibling functioning. Participants were 48 well siblings (aged 6-21 years) of children with LLCs and their parents.	The association between gender and frequency of well sibling communication was not statistically significant. (Jaaniste et al., 2021b) Analyses revealed a significant positive correlation between the frequency with which well siblings initiated conversations about the illness and the frequency with which they openly talked about death. (Jaaniste et al., 2021b) The strongest statistical predictors of amount of illness-related information provided to well siblings were well sibling age and amount of parental internal and external resilience resources. (Jaaniste et al., 2021b) Well siblings who were girls had significantly more communication regarding their sick brother or sister than well siblings who were boys. (Jaaniste et al., 2021b) Both well siblings and parents in the current sample were significantly more satisfied with familial communication relative to published normative data, but the correlation between parent- and well sibling-reported satisfaction with general familial communication was negligible. (Jaaniste et al., 2021b) Well siblings reported significantly lower familial expressiveness relative to the parent group, but not significantly different from the published adolescent normative data. (Jaaniste et al., 2021b) Sibling-rated familial cohesion was significantly greater than the normative data but not significantly different from the parent group. (Jaaniste et al., 2021b) Well siblings reported significantly lower familial conflict than the normative data. (Jaaniste et al., 2021b) When assessing the predictors of well sibling satisfaction with general familial communication, of all the factors considered, only well sibling reported familial cohesion was a statistically significant predictor. (Jaaniste et al., 2021b)

		The emotional functioning of well siblings was significantly positively correlated with familial cohesion and negatively correlated with familial conflict. (Jaaniste et al., 2021b) The social and school functioning variables were not significantly correlated with any of the familial communication variables. (Jaaniste et al., 2021b) Results of current study suggest that boys may be less likely than girls to initiate illness-related conversations and conversations about death. (Jaaniste et al., 2021b) Strongest statistical predictors of amount of illness-related communication between parents and well siblings were sibling age and parental resilience resources. … Parents may have found it easier to explain difficult concepts to older children. (Jaaniste et al., 2021b) Well siblings and parents were significantly more satisfied with familial communication than published norms among families that were not selected for having any serious medical conditions. Families in the current study may have had greater unity of purpose in their shared goal of caring for an unwell child, perhaps resulting in greater importance being placed on effective communication. (Jaaniste et al., 2021b) Negligible correlation between sibling and parental perceptions of general familial communication satisfaction…highlights importance of talking with different family members when considering familial communication, as perspectives may vary markedly. (Jaaniste et al., 2021b) There may be considerable individual variability in the desired amount of illness-related communication by well siblings; not all well siblings are likely to be satisfied with receiving more illness-related communication. Some children may find a lot of illness-related communication unhelpful or distressing. (Jaaniste et al., 2021b) Well siblings living in a household with a child with a serious illness may value the provision of emotional support as well as communication regarding non-illness-

		related issues (e.g. school, friends) (Jaaniste et al., 2020). (Jaaniste et al., 2021b) The current study found familial cohesion to be the only variable associated with the well siblings' satisfaction with familial communication. It is not clear whether more satisfying family communication leads to greater family cohesion, or whether greater cohesion leads to more satisfying communication. (Jaaniste et al., 2021b) Families that were more cohesive and with less conflict had well siblings with better emotional functioning. (Jaaniste et al., 2021b) Social and school functioning were not found to be significantly related with any of the family factors assessed. (Jaaniste et al., 2021b)
Understanding of Death and Dying in Children from Diverse Cultural Backgrounds with Life-Threatening Illnesses and Their Siblings (poster abstract) McPoland et al., 2017	Exploratory qualitative in-depth individual interview with children with life-threatening illnesses and their siblings	Preliminary results indicate that children with life-threatening illnesses and their siblings frequently worry about death and dying. (McPoland et al., 2017) Further, they have a mature understanding when compared to age-matched healthy children. (McPoland et al., 2017) Notable differences include an increased exposure to death and focus on faith as a means to understand their experience amongst the Haitian children. (McPoland et al., 2017)
Siblings caring for and about pediatric palliative care patients. Gaab et al., 2014	Semi-structured interviews with 18 siblings of pediatric palliative care (PPC) patients aged 9 to 22 in Auckland. Majority of participants	Themes of 'helping' and 'mortality' consistently arose. *Mortality*: Siblings observed deterioration in brother or sister's condition but death still came as surprise. (Gaab et al., 2014) Most siblings felt it was important to discuss the impending death to gain better understanding. Knowledge gave them greater appreciation of their sibling and resulted in spending more time with them.

	were bereaved.	They became more patient and accepting of the ill child. (Gaab et al., 2014) Several siblings mentioned feeling inexperienced and needing time to cope, prepare and seek comfort in the situation. (Gaab et al., 2014) Anger and fear when they were 'left in the dark'. Some didn't want friends to talk about the death of their sibling and many worried about losing the ill child. (Gaab et al., 2014) A couple suggested that it was more helpful to talk about how the ill child enjoys life than receiving pity or awkward sympathy. (Gaab et al., 2014) Siblings generally wanted to be informed of their ill siblings' health statuses but did not want death/mortality to be the topic of every conversation. (Gaab et al., 2014) *Helping*: most siblings talked about helping the ill child in their families; siblings wanted ill child to be happy so sang and joked with them, left them alone when required and comforted them. Siblings happy to sacrifice time with caregivers so that ill child could be looked after. Helping the ill child helped them. Friends who visited, prayed for and stuck around ill children were valued by the siblings. (Gaab et al., 2014) Important to be included in the care of ill children. (Gaab et al., 2014) Siblings value emotional, instrumental and informational support as the most helpful in their adjustment to having a chronically ill sibling. (Gaab et al., 2014) Siblings want to be involved in caring for their ill sibling. (Gaab et al., 2014) Being involved in the ill child's care and conversations about their general health status were discussed in mostly positive terms by the siblings interviewed. (Gaab et al., 2014)

		In order to fulfil young people’s cognitive and active coping styles, caregivers may involve them in caring for their brothers and sisters. (Gaab et al., 2014) Limitations: participants included both bereaved and nonbereaved siblings aged 9 to 22. Small sample not necessarily representative of population at large.
Grief Related to the Experience of Being the Sibling of a Child With Cancer Nolbris et al., 2014	Qualitative descriptive method was chosen based on open-ended interviews with 29 siblings aged 8 to 24 years. Qualitative content analysis applied to the interview data.	When the child’s cancer was confirmed, siblings experience anxiety and worry, describing the situation as one of suffering and anticipatory grief, which could occur soon after the diagnosis or in situations during their sibling’s treatment. (Nolbris et al., 2014) Siblings expressed a wish to have had someone to talk to about their thoughts and concerns regarding treatment and death. (Nolbris et al., 2014) Grief expanded to include awareness of the hard life that their ill sibling now had; the siblings found it hard to stand by helplessly. (Nolbris et al., 2014) The siblings described grief over their loss of a normal and happy childhood or youth when they compared them with their healthy friends. (Nolbris et al., 2014) The sick child could also be a victim of bullying, and the siblings often had to protect them at school. (Nolbris et al., 2014) During the treatment they continued to suffer from thoughts that things might go wrong and their ill sibling could die. If a disease relapse occurred, these thoughts became even worse. (Nolbris et al., 2014) The family was no longer the same as before. (Nolbris et al., 2014) The parents spent all their time with the ill sibling at the hospital or at home. (Nolbris et al., 2014) The well siblings perceived being excluded and needing to cope with worries and grief by themselves. (Nolbris et al., 2014)

		In the parents’ absence, both young and older siblings missed their attention and felt unimportant and forgotten. (Nolbris et al., 2014) They understood that the ill sibling had to be in the centre and the parents looked so broken and overloaded that the siblings did not ask for their attention. (Nolbris et al., 2014) The death of their sibling was described as shocking, and for the well siblings, despite all their worries, that their brother or sister could actually die was incomprehensible. (Nolbris et al., 2014) From the time of diagnosis, the focus had been about treatments and examinations, and a fatal outcome had rarely been discussed. (Nolbris et al., 2014) To survive daily life, they tried to avoid thinking about how they felt and what had happened to their deceased sibling. (Nolbris et al., 2014) To survive the process of grief, the well sibling sometimes took time to do something completely different, such as being with friends. (Nolbris et al., 2014) Studying also helped them, even if their inherent grief surfaced in various places and reminded them of their pain and the pressure they were under. (Nolbris et al., 2014) Later, when time had passed, they slowly began to think and to regain the courage to think, to reflect and accept what had happened. (Nolbris et al., 2014) They tried to find words to express and communicate the experiences of grief, not only in their own thoughts but also with family and friends. (Nolbris et al., 2014) A special bond was created between the siblings, and the experiences of grief may be influenced by this. (Nolbris et al., 2014)

		Siblings of all ages appear to need someone who understands them, listens to them, and allows them to speak freely without considering others. (Nolbris et al., 2014) One finding was that grieving seemed to give meaning to and strengthen the bond between the ill and well siblings. The well sibling felt some responsibility for the ill sibling's well-being. (Nolbris et al., 2014) Family life changed from the moment of diagnosis, with all priority given to the sick child, and the siblings felt that they were abandoned. (Nolbris et al., 2014) A predominant experience expressed by the siblings was one of sadness that continued even after the sick child had successfully completed treatment. The siblings' families were not always aware of this sadness. (Nolbris et al., 2014) The present study indicates a need for support of well siblings during their ill sibling's illness and death, which may help to prepare them to process the emotions that can occur and assure them that such feelings are normal when someone close to you dies. (Nolbris et al., 2014) Conversational support groups for siblings and using photos as tools to put difficult thoughts into words have been shown to reduce suffering through meeting others in the same situation. (Nolbris et al., 2014)
Adolescent siblings of children with cancer: a qualitative study from a salutogenic health promotion perspective Løkkeberg et al., 2020	Interview with seven female siblings aged 13-17. The interviews were transcribed and subjected to qualitative content analysis.	Main theme: New challenges and needs in everyday life. Subthemes: Cancer into life and Helpful resources to cope. (Løkkeberg et al., 2020) Lives were turned upside down suddenly when siblings learned that their brothers had developed cancer. (Løkkeberg et al., 2020) Cancer entering their lives affected the siblings in several ways and brought new concerns. (Løkkeberg et al., 2020) Some siblings were separated from their parents and families for varying durations, while others in the family stayed in the hospital. Some siblings stayed at home with

		grandparents and other healthy siblings, some stayed with friends, and some stayed "everywhere". Everyday life became different and unfamiliar. (Løkkeberg et al., 2020) While some felt left alone and lonely to a great extent and missed their families very much, others managed better. (Løkkeberg et al., 2020) The main focus in the families was moved from the usual issues to illness and treatment. (Løkkeberg et al., 2020) Siblings had to be more careful than before and could not act as they usually did with the family. (Løkkeberg et al., 2020) Precautions because of risk of infection (Løkkeberg et al., 2020) Siblings had to be quiet and careful all the time (Løkkeberg et al., 2020) Unable to be themselves completely (Løkkeberg et al., 2020) These things could make them tired of the situation (Løkkeberg et al., 2020) Time around the diagnosis described as scary and painful (Løkkeberg et al., 2020) Diagnosis was a shock, everything felt new, strange and hard to believe, and some did not know how to react (Løkkeberg et al., 2020) Seeing parents cry for first time (Løkkeberg et al., 2020) Informants described themselves as vulnerable, anxious and sad (Løkkeberg et al., 2020) They felt afraid, worried and curious about what would happen (Løkkeberg et al., 2020)

		Hard to concentrate at school and to sleep at night (Løkkeberg et al., 2020) Others did not understand the seriousness of the situation (Løkkeberg et al., 2020) The cancer could be both painful and scary (Løkkeberg et al., 2020) Siblings had to deal with cancer as a potentially fatal disease (Løkkeberg et al., 2020) Siblings aware of the nature of the cancer and afraid of relapse for a long time after treatment was finished (Løkkeberg et al., 2020) Siblings could feel lonely, mainly because they thought no one could understand (Løkkeberg et al., 2020) Trying to make others understand described as stressful (Løkkeberg et al., 2020) Some did not talk to friends because they found it difficult to explain (Løkkeberg et al., 2020) When friends expressed that they understood, without actually doing so, it could increase feelings of loneliness and sadness (Løkkeberg et al., 2020) Siblings could feel different from others. One said she felt like she was “being on another human level” (Løkkeberg et al., 2020) Siblings found it difficult to share their thoughts and feelings with others, partly because they thought that friends did not understand (Løkkeberg et al., 2020) One informant said that she kept everything inside her mind because she was afraid to say something wrong and make things worse (Løkkeberg et al., 2020) One sibling described a situation at school when she started to cry and was left by her teacher to comfort herself (Løkkeberg et al., 2020)

		Some siblings would not “bother” friends by talking about their feelings because they might not know what to say, and they were worried about pushing their friends away (Løkkeberg et al., 2020) Siblings could feel jealous and lonely within the family, as a result of the sick children’s needs for attention and care (Løkkeberg et al., 2020) Siblings were given increased responsibility to plan and organise their changed daily lives in their parents’ absence (Løkkeberg et al., 2020) Siblings described growing and developing themselves, becoming stronger and more resistant than before, and gaining increased ability to understand others (Løkkeberg et al., 2020) Siblings used words describing new and expanded life perspectives for appreciating themselves and others as being healthy (Løkkeberg et al., 2020) Having someone to talk to when they needed it was the most important factor helping them to cope during the illness period (Løkkeberg et al., 2020) Staying with friends could be difficult but also good and helpful (Løkkeberg et al., 2020) Being active with friends could make the siblings think of something else other than the disease (Løkkeberg et al., 2020) Support from friends could mean a lot, and it felt good to receive hugs and comfort (Løkkeberg et al., 2020) Friends could be quite honest and say things as they were, unlike adults who could be more protective Siblings needed to be themselves without anyone feeling sorry for them or having any expectations of how they should cope with the situation (Løkkeberg et al., 2020)

		It was important not to be identified with the disease, as "she with the sick brother". (Løkkeberg et al., 2020) Stable and caring persons, such as grandparents, aunts and uncles, their own siblings, or friends of the families, helped to make the experience easier (Løkkeberg et al., 2020) Meeting others with similar experiences and worries, could create feelings of normality, safety and comfort (Løkkeberg et al., 2020) Understanding was a central need and an important prerequisite for having faith and hope. Information given by hospital staff or parents could increase their understanding (Løkkeberg et al., 2020) Siblings' own understanding could give them confidence to talk to others about what had happened and have the knowledge to answer questions, so this was helpful in relationships with others (Løkkeberg et al., 2020) Informing the class could increase understanding (Løkkeberg et al., 2020) While some did not want to share information with their class because they wished everything to stay as normal as possible, others preferred that their classmates be informed about the cancer disease (Løkkeberg et al., 2020) Knowing that everything was good at the hospital was described as a prerequisite for coping (Løkkeberg et al., 2020) Praying to God, hoping and believing in a good outcome, and shutting out fears of a bad outcome were examples of positive coping strategies (Løkkeberg et al., 2020) Some preferred being consecutively informed about what was going on at the hospital. Others benefited from living as normally as possible with distance from the illness and its treatment, and without knowing everything that happened (Løkkeberg et al., 2020)

		Pressure at school could make the days more difficult and make them feel tired. On the other hand, it could be good to be at school (Løkkeberg et al., 2020) One teacher had made a call to a family member during the summer vacation to prepare for the start of school for the sibling, and to clarify whether she had any extra needs (Løkkeberg et al., 2020) Others told about teachers being available for talking and teachers adapting schoolwork and lowering requirements for a while (Løkkeberg et al., 2020) Normal family activities were mentioned as important and could make the sibling feel better (Løkkeberg et al., 2020) Siblings underlined the important of visiting their families in the hospital, having time with others in the family and being comforted by their parents (Løkkeberg et al., 2020) Strong family ties were described and together with the family they could cry, smile, laugh and share feelings, and be completely themselves (Løkkeberg et al., 2020)
Emotional Experiences Among Siblings of Children With Rare Disorders Haukeland et al., 2015	Thematic analysis of participant dialogue from 20 sessions with 11 different support groups for healthy siblings of children with rare disorders	Some statements reflected emotions related to either possessing or lacking *information* or *knowledge* about the disorder itself (Haukeland et al., 2015) Sadness was described as a reaction to being informed about the disorder, but this emotion was sometimes mixed with a feeling of relief (Haukeland et al., 2015) Emotions such as anger, irritation and sadness were described, but also that feelings of compassion and empathy were evoked through inferring the mental state of their sibling (Haukeland et al., 2015) Degree to which the disorder was anxiety provoking was varying and participants' feelings about the medical condition ranged from acceptance to denial (Haukeland et al., 2015)

		Beneficial experiences caused by the disorder, such as enjoying using the wheelchair or other special aids of the siblings, were also described (Haukeland et al., 2015) Thinking about the prognosis of the disorder lead to worry and a variety of negative emotions such as fear, nervousness, sadness and grief (Haukeland et al., 2015) Participants described emotional distress in relation to the possible or probable early death of their sibling (Haukeland et al., 2015) Practical implications – how the family had to adjust to the affected siblings – followed by descriptions of this being sad, difficult or uncomfortable (Haukeland et al., 2015) Comparisons with a normative standard of family life evoked feelings of jealousy or sadness (Haukeland et al., 2015) Participants described how they could get extra duties (Haukeland et al., 2015) Role or responsibility of having a sibling with a chronic disorder could imply a restriction of social activities and interactions with peers (Haukeland et al., 2015) Feelings of jealousy could be felt toward friends or other families that live "normal lives" (Haukeland et al., 2015) Siblings perceived restrictions the disorder put on their brother or sister. This could be a source for negative feelings, owing to the lost opportunities of doing "normal" sibling activities together that they caused (Haukeland et al., 2015) **Differential treatment of siblings (amount of care, affection, attention, time, and parenting style) by mostly parents, but also grandparents or people outside the family** (Haukeland et al., 2015)

		Taking siblings’ perspective and thinking about how it is like for them to live with the disorder were described to evoke negative emotions (Haukeland et al., 2015) Signs of reciprocity in the relationship seemed to be a source of positive emotions about the sibling relationship when participants experienced their brother or sister caring for them (Haukeland et al., 2015) A perceived lack of such reciprocity could cause negative emotions (Haukeland et al., 2015) *Reflections about (ab)normality* concerned how the deviant behaviour of their sibling affected them and varied from not being bothered to feeling embarrassed, angry and/or irritated (Haukeland et al., 2015) Participants described their sibling being teased or bullied by other children and the difficult emotions this evoked, from negative to reflecting about the positive consequences of the episodes, such as becoming more aware of one’s own or the family’s coping resources (Haukeland et al., 2015) Participants described their mixed emotions about the disorder of the sibling (Haukeland et al., 2015) Descriptions of worries for the future were often accompanied by statements about positive emotions toward siblings (Haukeland et al., 2015) Positive experiences of enrichment resulting from their life with a sibling with a rare or severe disorder were also described, in addition to the more negative emotional experiences (Haukeland et al., 2015) These enriching experiences were related to activities the family do together as a way of coping with the situation, or to personal growth stemming from their experience as siblings (Haukeland et al., 2015) Participants also described experiencing contradictory feelings (Haukeland et al., 2015)

		Some participants described taking explicit actions, such as talking with someone, working out, closing the door to one's room, or listening to music to cope with negative emotions (Haukeland et al., 2015) A few participants explicitly described such actions as a means to create a space of their own or something that was uniquely theirs. In other cases, these strategies appeared to be ways of escaping difficult emotions, such as jealousy (Haukeland et al., 2015) A frequently described passive coping strategy was trying to accept the situation (Haukeland et al., 2015) Some participants described sharing their negative emotions with parents, friends, or siblings as a means to cope. More common, however, were statements about not communicating or hiding emotions (Haukeland et al., 2015) NB: Age was found to be positively correlated with number of statements. No group differences in number of statement statements were found based on gender, or between sibling of children with somatic versus cognitive disorders or progressive versus stable disorders. One gender difference was found: girls talked more about coping through sharing or hiding emotions compared with boys.

Appendix D.

Descriptive Themes From the Literature Review

Theme 1: Needs of siblings

1. Challenges of having a sibling with CMN
2. Unmet needs of siblings
3. Individual preferences
4. Knowledge about sibling's illness
5. Communication with others

Theme 2: Emotional experience of siblings

1. Negative emotions experienced
2. Positive aspects of having a sibling with CMN
3. Coping mechanisms/support
4. Responsibility / maturity
5. Changes to 'the norm'
6. The future

Theme 3: Relationship with family

1. Familial cohesion
2. Bond with siblings
3. Difference in parents
4. Discrepancy between parent and child views
5. **Differential treatment of sibling**

Theme 4: The world outside the home

1. Compartmentalising
2. School factors
3. Friendships
4. Identity
5. Gender/cultural differences

Appendix E.

Application for Research Ethics Approval

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

(Updated October 2021)

FOR BSc RESEARCH;

MSc/MA RESEARCH;

PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Section 1 – Guidance on Completing the Application Form

(please read carefully)

1.1	Before completing this application, please familiarise yourself with: ▪ British Psychological Society's Code of Ethics and Conduct ▪ UEL's Code of Practice for Research Ethics

	▪ UEL's Research Data Management Policy ▪ UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: ▪ If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. ▪ Useful websites: https://www.myresearchproject.org.uk/Signin.aspx https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/ ▪ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. ▪ HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example.

	▪ The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: ▪ Study advertisement ▪ Participant Information Sheet (PIS) ▪ Participant Consent Form ▪ Participant Debrief Sheet ▪ Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) ▪ Permission from an external organisation (see section 7) ▪ Original and/or pre-existing questionnaire(s) and test(s) you intend to use ▪ Interview guide for qualitative studies ▪ Visual material(s) you intend showing participants

Section 2 – Your Details

2.1	**Your name:**	**Deborah Woolfson**
2.2	**Your supervisor's name:**	**Dr Helena Bunn**
2.3	**Name(s) of additional UEL supervisors:**	**TBC** 3rd supervisor (if applicable)
2.4	**Title of your programme:**	**Doctorate in Educational & Child Psychology**
2.5	**UEL assignment submission date:**	**21/04/2023** Re-sit date (if applicable)

Section 3 – Project Details

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.

3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	**The lived experiences of siblings of children with complex medical needs: an interpretative phenomenological analysis**
3.2	**Summary of study background and aims (using lay language):**	**The study will explore how siblings of children and young people with complex medical needs experience family life and school; based on the findings, recommendations will be made to schools and Educational Psychologists to best support them.**

3.3	**Research question(s):**	**What are the lived experiences of siblings of children and young people with complex medical needs? How do siblings of children and young people with complex medical needs experience family life? How do siblings of children and young people with complex medical needs experience school? How do siblings of children and young people with complex medical needs envisage their ideal school?**
3.4	**Research design:**	**Qualitative - semi-structured interviews**
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	**Six to eight participants aged 11 to 18, with a brother or sister with complex medical needs. Inclusion criteria will be siblings (including full, half-, step-, adopted, fostered or bereaved sibling) of children aged 0 to 25 with complex medical needs who live together at least 50% of the time, speak English and attend an educational setting full- or part-time in the United Kingdom. Exclusion criteria will be children or young people who have complex medical needs themselves, or who are not aware of their brother or sister's complex medical needs.**
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	**An advert will be shared with the charity, The Maypole Project, who will publish the advert in its newsletter which will be sent by e-mail and/or post. The charity may also publish the advert on its website and/or on its social media pages (e.g. Facebook). If insufficient numbers of participants are recruited, other charities which serve the families of children with complex medical needs will be approached to request that they share the advert with service users in the same way.**

3.7	**Measures, materials or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	**The instructions for 'Drawing the Ideal School' (Williams & Hanke, 2007) are freely available online. No other measures, materials or equipment will be required.**	
3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	**Participants will be asked a series of questions in a face-to-face (or online) semi-structured interview. The main subjects to be covered will be pre-planned but additional follow-up questions may be asked depending on individual responses. During the interview, participants will also be asked to complete 'Drawing the Ideal School' (Williams & Hanke, 2007) where they will be asked to draw and describe their non-ideal and ideal school and various features associated with these.**	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	If you selected yes, please provide more information here	
3.10	**Will participants be reimbursed?**	**YES** ☐	**NO** ☒
	If yes, please detail why it is necessary.	If you selected yes, please provide more information here	
	How much will you offer?	Please state the value of vouchers	

	Please note - This must be in the form of vouchers, not cash.	
3.11	**Data analysis:**	**Data will be analysed using interpretative phenomenological analysis (IPA), a reflexive method of analysis which requires the researcher to recognise their own standpoint as they examine the data (Smith et al., 2009).**

Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.

4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.	Please detail how data will be anonymised	
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	**All identifying information will be removed during transcription; pseudonyms will be used; any detail in the text which could potentially identify individuals or schools will be generalised.**	

4.3	**How will you ensure participant details will be kept confidential?**	**Participants will be asked to choose a pseudonym and one for their brother or sister. Participants will not be asked for the name of their school or any other personal details. Contact details of the parents of participants will be stored separately from the child's interview transcript. If a participant mentions any information that could be used to identify them, their sibling or their school, this information will be anonymised at the transcription stage.**
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	**Audio recordings will be stored only until transcription has been completed. They will then be permanently deleted. Transcriptions and analysed data will be stored securely on the researcher's UEL OneDrive account. Transcriptions will be stored in a password protected document on a password protected user account.**
4.5	**Who will have access to the data and in what form?** (e.g., raw data, anonymised data)	**Anonymised data will be accessible to the researcher and the researcher's supervisor at the University of East London.**
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	**No data will be retained due to the sensitivity of the subject matter and vulnerability of participants (siblings of children with complex medical needs). Furthermore, retaining data for future research may reduce the chances of recruitment by adding what may be perceived by parents and children as an additional layer of vulnerability.**
4.7	**What is the long-term retention plan for this data?**	**All data will be destroyed after 3 years.**

4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐
4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐

	If yes, what are these, and how will they be minimised?	**It is not anticipated that participants will be adversely affected by taking part in the research. Nevertheless, it is still possible that participation – or its after-effects – may be challenging, distressing or uncomfortable in some way. Participants will be signposted to resources/services helpful in relation to obtaining information and support.**		
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☐	**NO** ☒	
	If yes, what are these, and how will they be minimised?	Please detail the potential risks and include measures you will take to minimise these for yourself as the researcher		
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:**	**YES** ☒		
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☒	**NO** ☐	**N/A** ☐
5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐	
	If yes, where?	**The Maypole Project office, participant's school or online.**		

5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒
	If yes, where?	Please state the country and other relevant details	
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	**YES** ☐	
5.7	**Additional guidance:** ▪ For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on ‘sign in’ and then ‘register here’ using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. ▪ For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor).		

	- For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor). - Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

Section 6 – Disclosure and Barring Service (DBS) Clearance

6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☒	**NO** ☐
	* You are required to have DBS or equivalent clearance if your participant group involves: (1) Children and young people who are 16 years of age or under, or (2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant		

	group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** ☒	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** ☒	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	**001709786282**	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	**Additional guidance:** ▪ If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian). ▪ For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.		

Section 7 – Other Permissions

7.1	**Does the research involve other organisations (e.g., a school,**	**YES**	**NO**

	charity, workplace, local authority, care home, etc.)?	☒	☐
	If yes, please provide their details.	**The Maypole Project, 51 High St, Green Street Green, Orpington BR6 6BQ. Registered charity no. 1120163. Company No. 06163173.**	
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	**YES** ☒	
7.2	**Additional guidance:** ▪ Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation’ or with the title of the organisation. This organisational consent form must be signed before the research can commence. ▪ If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.		

Section 8 – Declarations

8.1	**Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:**	**YES** ☒
8.2	**Student's name:** (Typed name acts as a signature)	**Deborah Woolfson**
8.3	**Student's number:**	**U1821236**
8.4	**Date:**	**14/01/2022**
Supervisor's declaration of support is given upon their electronic submission of the application		

Appendix F.

Ethics Committee Decision letter

University of East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details	
Reviewer:	**Paula Corredor Lopez**
Supervisor:	**Helena Bunn**
Student:	**Deborah Rose Woolfson**
Course:	**Prof Doc Educational and Child Psychology**
Title of proposed study:	**The lived experiences of siblings of children and young people with complex medical needs: an interpretative phenomenological analysis**

Checklist
(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐

Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐

Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher’s personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options

APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student’s confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate’s ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision: **Approved, v minor amendments**	Please select your decision

Minor amendments

Please clearly detail the amendments the student is required to make

The only thing I would say is think about wording like ‘respository’ and ‘pseudonym’ on the childrens’ participation sheet: think for 11yr olds would want this wording more accessible.

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☐**x**	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	

If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:

HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐

LOW	Approve and if necessary, include any recommendations in the below box.	☐
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature	
Reviewer: (Typed name to act as signature) Dr Paula Corredor Lopez	Click or tap here to enter text
Date: 01/02/22	Click or tap to enter a date
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee	

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	**Deborah Woolfson**

Student number:	**U1821236**
Date:	**04/02/2022**
Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required	

Appendix G.

Change of Title Request Form

School of Psychology Ethics Committee

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for a proposed title change to an ethics application that has been approved by the School of Psychology

By applying for a change of title request, you confirm that in doing so, the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed, then you are required to complete an 'Ethics Application Amendment Form'.

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	Using your UEL email address, email the completed request form along with associated documents to Dr Jérémy Lemoine (School Ethics Committee Member): j.lemoine@uel.ac.uk
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

Required documents

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Deborah Rose Woolfson**
Programme of study:	**Doctorate in Educational & Child Psychology**
Title of research:	**The Lived Experiences of Siblings of Children With Complex Medical Needs**
Name of supervisor:	**Dr Helena Bunn**

Proposed title change

Briefly outline the nature of your proposed title change in the boxes below

Old title:	**The Lived Experiences of Siblings of Children and Young People With Complex Medical Needs**
New title:	**The Lived Experiences of Siblings of Children With Complex Medical Needs**
Rationale:	This was the original title and 'children' is used to denote children and young people throughout the research. An ethics amendment form was submitted with the addition of 'and Young People' in the title in error and now requires amendment.

Confirmation

Is your supervisor aware of your proposed change of title and in agreement with it?	**YES** ☒	**NO** ☐
Does your change of title impact the process of how you collected your data/conducted your research?	**YES** ☐	**NO** ☒

Student's signature

Student: (Typed name to act as signature)	**Deborah Rose Woolfson**
Date:	**17/04/2024**

Reviewer's decision		
Title change approved:	**YES** ☒	**NO** ☐
Comments:	**There was a mismatch between titles. The title change will not impact the process of how the data are collected or how the research is conducted.**	
Reviewer: (Typed name to act as signature)	**Dr Jérémy Lemoine**	
Date:	**17/04/2024**	

Appendix H.

Ethics Amendment Request Form (a)

University of
East London

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents	
A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details	
Name of applicant:	**Deborah Woolfson**
Programme of study:	**Professional Doctorate in Educational and Child Psychology**
Title of research:	**The Lived Experiences of Siblings of Children and Young People with Complex Medical Needs: An Interpretative Phenomenological Analysis**
Name of supervisor:	**Dr Helena Bunn**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
To allow participants to be recruited via schools, social media and personal contacts.	I have been unable to recruit sufficient participants via charities so have decided to seek participants via other avenues.
To allow interviews to take place in the participant's home or other suitable location, e.g. young carer's hub or local authority office.	It has not been possible to agree and book an appropriate location in which to undertake participant interviews from those originally stated in the Ethics application and risk assessment.
To expand the age range of potential participants from 11-18 to 10-19.	I have been unable to recruit sufficient participants within the original age range so I have decided to expand the potential pool from which I can recruit.

Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

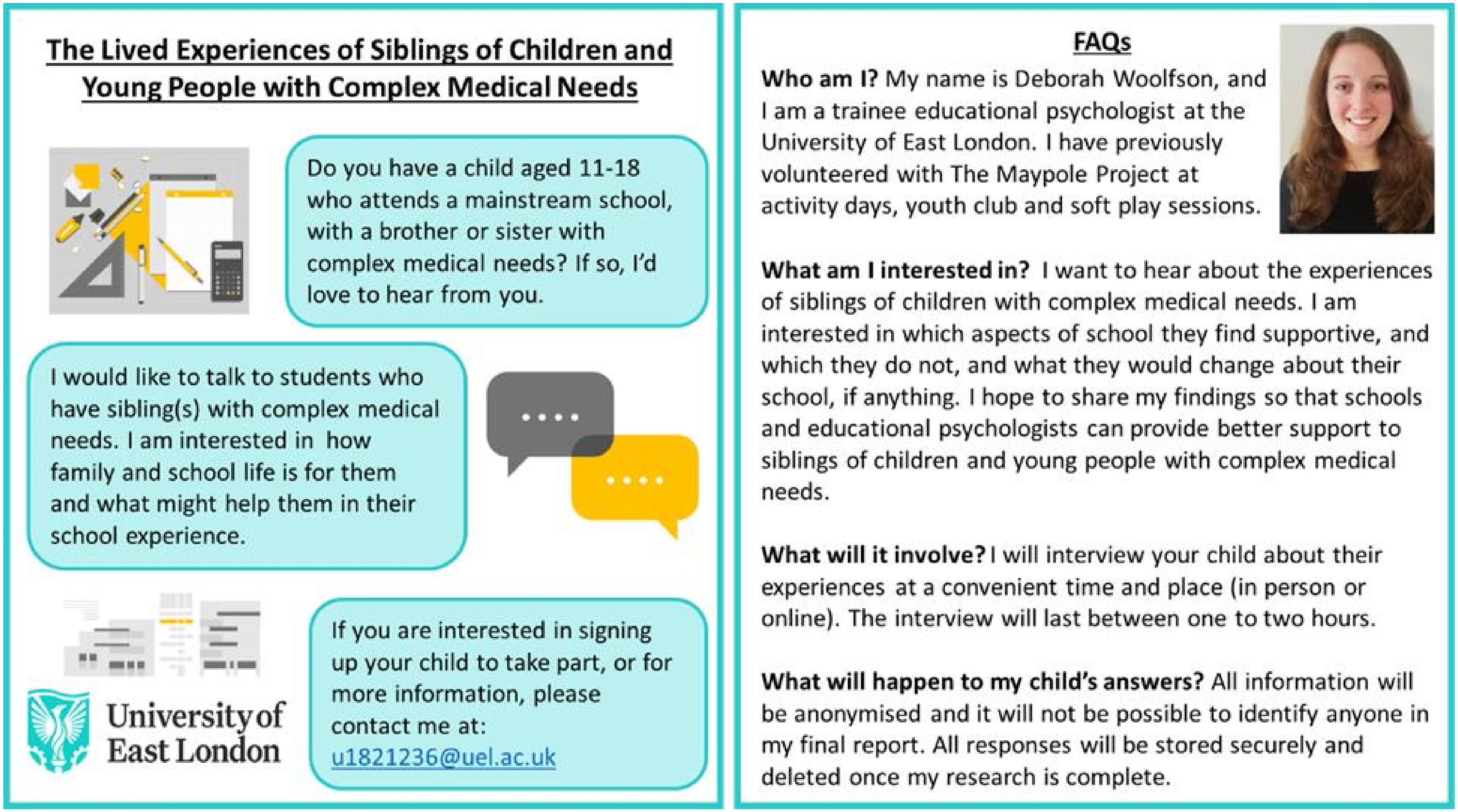
Student: DRWoolfson	**Deborah Rose Woolfson**
Date:	**13/10/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	**1. Please ensure personal accounts are not used to advertise or recruit participants (i.e., researcher not to use their personal account).** **2. Please ensure written permission is gained from charities/schools to confirm they will support with recruitment.**	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**17/10/2023**	

Appendix I.

Recruitment Advert



The Lived Experiences of Siblings of Children and Young People with Complex Medical Needs

Do you have a child aged 11-18 who attends a mainstream school, with a brother or sister with complex medical needs? If so, I'd love to hear from you.

I would like to talk to students who have sibling(s) with complex medical needs. I am interested in how family and school life is for them and what might help them in their school experience.

University of East London

If you are interested in signing up your child to take part, or for more information, please contact me at: u1821236@uel.ac.uk

FAQs

Who am I? My name is Deborah Woolfson, and I am a trainee educational psychologist at the University of East London. I have previously volunteered with The Maypole Project at activity days, youth club and soft play sessions.

What am I interested in? I want to hear about the experiences of siblings of children with complex medical needs. I am interested in which aspects of school they find supportive, and which they do not, and what they would change about their school, if anything. I hope to share my findings so that schools and educational psychologists can provide better support to siblings of children and young people with complex medical needs.

What will it involve? I will interview your child about their experiences at a convenient time and place (in person or online). The interview will last between one to two hours.

What will happen to my child's answers? All information will be anonymised and it will not be possible to identify anyone in my final report. All responses will be stored securely and deleted once my research is complete.

Appendix J.

Ethics Amendment Request Form (b)

University of East London

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Deborah Woolfson**
Programme of study:	**Professional Doctorate in Educational and Child Psychology**
Title of research:	**The Lived Experiences of Siblings of Children and Young People with Complex Medical Needs: An Interpretative Phenomenological Analysis**
Name of supervisor:	**Dr Helena Bunn**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
To give participants a £10 voucher for a store of their choice as a token of thanks for their participation.	I have been unable to recruit sufficient participants and would like to offer a token of thanks to encourage potential participants to come forward.
To allow participants to be recruited via schools, social media and personal contacts.	I have been unable to recruit sufficient participants via charities so have decided to seek participants via other avenues.
To allow interviews to take place in the participant's home or other suitable location, e.g. young carer's hub or local authority office.	It has not been possible to agree and book an appropriate location in which to undertake participant interviews from those originally stated in the Ethics application and risk assessment.
To expand the age range of potential participants from 11-18 to 10-19.	I have been unable to recruit sufficient participants within the original age range so I have decided to expand the potential pool from which I can recruit.

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: DRWoolfson	**Deborah Rose Woolfson**
Date:	**13/11/2023**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	Recruitment via schools, please ensure written permission is obtained. Recruitment via social media, please ensure that separate accounts are set up for the research (i.e., do not use personal accounts). Please ensure this new information is included in all study materials, for example, offer of a voucher and interview to be conducted in the participant's home (e.g., PIS).	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	

Appendix K.

Information Sheet for Parents

Version: 3
Date: 13/11/2023

PARENT/CARER OF PARTICIPANT INFORMATION SHEET

The lived experiences of siblings of children and young people with complex medical needs

Contact person: Deborah Woolfson
Email: u1821236@uel.ac.uk

Your child is being invited to participate in a research study. Before you decide whether to allow your child to take part or not, please carefully read through the following information which outlines what their participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Deborah Woolfson. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Doctorate in Educational and Child Psychology. As part of my studies, I am conducting the research that your child is being invited to participate in.

What is the purpose of the research?

I am conducting research into the views of siblings of children with complex medical needs, including their experiences of family life and school. It is hoped that this research can help schools and Educational Psychologists (people who help schools to ensure pupils achieve their potential) to provide the best possible support for the siblings of children with serious illnesses.

Why have I been invited to take part?
To address the study aims, I am inviting siblings of children with complex medical needs to take part in my research. If your child is a young person aged 10 to 19 and has a brother or sister with complex medical needs, they are eligible to take part in the study.

It is entirely up to you and your child whether they take part or not, participation is voluntary.

What will I be asked to do if I agree to take part?
If you agree to your child taking part, they will be asked to take part in an interview about their experience of family life and school. The interview will be more like an informal chat, and they do not need to answer any questions they do not want to answer.

It is expected that the meeting will take no more than two hours. It will take place at either your child's school, the University of East London Stratford Campus, your own home or another suitable location agreed between you, your child and the researcher. Alternatively, if you and your child wish, the meeting can take place online using Microsoft Teams.

The interview will be audio recorded using a digital voice recorder.

Can I change my mind?
Yes, you or your child can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw your child from the interview, you can do so by telling me at any time. If you withdraw your consent for your child to participate, your child's data will not be used as part of the research.

Separately, you can also request to withdraw your child's data from being used even after they have taken part in the study, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Are there any disadvantages to taking part?

- It can be upsetting to think and talk about life with a brother or sister who has complex medical needs. If your child becomes upset during the interview, we can take a pause or end the interview if you wish.
- I will be sensitive when asking questions and your child does not need to answer anything they do not want to. The questions will not ask for details of their brother or sister's illness, but rather what their experience of family life and school is like.

- Information about organisations that can support you and your child will be provided.

How will the information I provide be kept secure and confidential?

- Participants will not be identified by the data collected, on any material resulting from the data collected, or in any write-up of the research. Pseudonyms will be used to protect your child's identity and that of anyone else they mention.
- Your contact details will be securely stored on the researcher's UEL OneDrive account. They will only be stored for the duration of the study and then destroyed.
- Research data will be securely stored in the researcher's UEL OneDrive account.
- If necessary, data will be transferred using secure UEL emails.
- Only the researcher and her supervisor will have access to anonymised data.
- Any potentially disclosive statements will be replaced with more general text. For example, if a participant talks about their sibling's medical needs which make them identifiable due to the specificity/rarity, the text will be replaced with more general text about the nature or complexity of the child's needs.
- The researcher, her supervisor and examiners will see the anonymised data.
- Interview recordings will be destroyed after they have been transcribed.
- The contact details of participants' parents will not be available to anyone except the researcher, and these will be destroyed following the sharing of the published research.
- If it is deemed during the interview that there is a risk to self or others, confidentiality may need to be broken.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (Registry of Open Access Repositories, ROAR). The intention is that findings will also be disseminated to a range of audiences (e.g., academics, schools, Educational Psychologists, etc.) through journal articles, conference presentations, charity newsletters and websites. In all material produced, your child's identity will remain anonymous, in that it will not be possible to identify them personally. Their quotes may be used under a pseudonym but any personally identifying information will be removed.

You and your child will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr Helena Bunn for 3 years, following which all data will be deleted.

Who has reviewed the research?
My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me, Deborah Woolfson, at: u1821236@uel.ac.uk.

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Helena Bunn, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: h.bunn@uel.ac.uk

or

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

Appendix L.

Information Sheet for Participants

Version: 3
Date: 13/11/2023

PARTICIPANT INFORMATION SHEET

The lived experiences of siblings of children and young people with complex medical needs
Contact person: Deborah Woolfson
Email: u1821236@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Deborah Woolfson. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Doctorate in Educational and Child Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

What is the purpose of the research?

I am conducting research into the views of siblings of children who have complex medical needs, including their experiences of family life and school. It is hoped that this research can help schools and Educational Psychologists (people who help schools to ensure pupils achieve their potential) to provide the best possible support for the brothers and sisters of children with illnesses.

Why have I been invited to take part?

To address the study aims, I am inviting siblings of children with complex medical needs to take part in my research. If you are a young person aged 10 to 19 and have a brother or sister with complex medical needs, you are eligible to take part in the study.

It is entirely up to you and your parent/carer whether you take part or not, participation is voluntary.

What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to take part in an interview about your experience of family life and school. The interview will be more like an informal chat, and you do not need to answer any questions you do not want to answer.

It is expected that the meeting will take no more than two hours. It will take place at your school, the University of East London Stratford Campus, your own home or another suitable location agreed between you, your parent/carer and the researcher. Alternatively, if you wish, the meeting can take place online using Microsoft Teams.

The interview will be audio recorded using a digital voice recorder.

Can I change my mind?

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw from the interview, you can do so by telling me at any time. If you withdraw, your data will not be used as part of the research.

Separately, you can also request to withdraw your data from being used even after you have taken part in the study, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Are there any disadvantages to taking part?

- It can be upsetting to think and talk about life with a brother or sister who has complex medical needs. If you become upset during the interview, we can take a pause or end the interview if you wish.

  - I will be sensitive when asking questions and you do not need to answer anything you do not want to. The questions will not ask for details of your brother or sister's illness, but rather what your experience of family life and school is like.
  - Information about organisations that can support you will be provided.

How will the information I provide be kept secure and confidential?

- Participants will not be identified by the data collected, on any material resulting from the data collected, or in any write-up of the research. Names will be changed to protect your identity and that of anyone else you mention.
- Your parent or carer's contact details will be securely stored on the researcher's UEL OneDrive account. They will only be stored for the duration of the study and then destroyed.
- Research data will be securely stored in the researcher's UEL OneDrive account.
- If necessary, data will be transferred using secure UEL emails.
- Only the researcher and her supervisor will have access to anonymised data.
- Any potentially disclosive statements will be replaced with more general text. For example, if a participant talks about their sibling's medical needs which make them identifiable due to the specificity/rarity, the text will be replaced with more general text about the nature or complexity of the child's needs.
- The researcher, her supervisor and examiners will see the anonymised data.
- Interview recordings will be destroyed after they have been transcribed.
- The contact details of participants will not be available to anyone except the researcher, and these will be destroyed following the sharing of the published research.
- If it is deemed during the interview that there is a risk to self or others, confidentiality may need to be broken.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online data store (Registry of Open Access Repositories, ROAR). The intention is that findings will also be shared with a range of audiences (e.g., academics, schools, Educational Psychologists, etc.) through journal articles, conference presentations, charity newsletters and websites. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally. Your quotes may be used but names will be changed and any personally identifying information will be removed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr Helena Bunn 3 years, following which all data will be deleted.

Who has reviewed the research?
My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me, Deborah Woolfson, at: u1821236@uel.ac.uk.

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Helena Bunn, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: h.bunn@uel.ac.uk

or

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

Appendix M.

Parent Consent Form

University of
East London

CONSENT TO PARTICIPATE IN A RESEARCH STUDY – Parent/Carer form

The lived experiences of siblings of children and young people with complex medical needs: an interpretative phenomenological analysis

Contact person: Deborah Woolfson

Email: u1821236@uel.ac.uk

	Please initial
I confirm that I have read the parent/carer of participant information sheet dated 23/09/2022 (version 2) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my child's participation in the study is voluntary and that I may withdraw my consent for my child to participate at any time, without explanation or disadvantage.	
I understand that if my child withdraws during the study, my child's data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my child's data from the study.	
I understand that the interview will be recorded using a digital voice recorder.	
I understand that my child's personal information and data, including audio recordings from the research, will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	

It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my child's interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me or my child.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree for my child to take part in the above study.	

Name of Parent/Carer of Participant (BLOCK CAPITALS)

……

Participant's Name (BLOCK CAPITALS)

……

Parent/Carer's Signature

……

Researcher's Name (BLOCK CAPITALS)

……

Researcher's Signature

……

Date

……

Appendix N.

Participant Assent Form

University of East London

ASSENT TO PARTICIPATE IN A RESEARCH STUDY – Participant form

The lived experiences of siblings of children and young people with complex medical needs
Contact person: Deborah Woolfson
Email: u1821236@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 13/11/2023 (version 3) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using a digital voice recorder.	
I understand that my personal information and data, including audio recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	

I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS)

………

Participant’s Signature

………

Researcher’s Name (BLOCK CAPITALS)

………

Researcher’s Signature

………

Date

………

Appendix O.

Interview Schedule

Focus area	**Examples of questions and probes**
Pre-amble: Study and participant introduction	What do you understand this study to be about? Check happy to carry on (assent) I understand you have a sibling with complex medical needs, can you tell me a bit about them?
Confidentiality	Pseudonyms – ask CYP to choose
Family life	Tell me about your relationship with your sibling (with complex medical needs). *Prompts – what do you do at the weekend? Has it always been like this?* Do you have any particular memories with your sibling that stand out? Tell me about your relationship with your parents/carers. *Prompts: what do you usually do with them? Do they work?* How would you describe a typical day in your family?
School experience	Tell me about your time at primary school. - How did/do you get along with peers/teachers? - Have you been to one or more schools? (e.g. infant and junior) - What is most memorable for you from primary? - Anything else? Tell me about your experience of secondary school. - Do you enjoy going to school? - What is most memorable for you?
Interaction between family life and school experience	Do you think having X as your brother/sister has any influence on how school is for you? How so? Do you think that what happens at school affects your time with X? How?
Ideal school	With everything we have talked about, how would you describe your ideal school? Is there any part of these that are similar to your current school experience?

Experts by experience	You have so much insight/expertise into the lived experience of siblings of CYP with CMN, Is there anything you think all schools should do differently to support siblings of children and young people with complex medical needs?
Anything I've missed	Anything else you want to tell me?

Appendix P.

Example Annotated Interview Transcript

Emergent themes	Original transcript	Exploratory notes
	Interviewer: Could you tell me a bit about Moo?	
1-Sibling's regression at around 18 months	Paige: Well, I mean, I'm pretty sure it was when she was eight months old, no, eighteen, was it months or weeks? Months, when she was 18 months old, just before that, she was learning like, well, she already learnt how to run, she was talking, like, she was just doing lots of stuff, she was eating properly, but, after she turned 18 months, she started losing all of her abilities.	Uncertainty about sibling's age at time of regression *Says she's 'pretty sure' to mean she's not sure* Talks about what sister used to be able to do as opposed to what she can do – is she more affected by the loss than the inability itself? Who is most affected?
	Interviewer: Ah, okay.	
	Paige: But, she, she goes like, really floppy in the mornings. She has, I can't remember what it's called, that thingy up her nose.	*Floppy – evocative/sensory* Can't remember name – *childish language contrast with maturity of subject* Looks to parent for answer – seeking reassurance from parent?
	Parent: NG tube	
2-Pride in helping to feed sibling	Paige: NG tube yeah. I help feed as well, with mum as well. Um…	Proud of helping
	Interviewer: What's that like?	
3-Difficulty dressing her sibling 4-Difficulty explaining sister's seizures	Paige: Um, it's quite, it's quite hard to be honest in the mornings 'cause when you're trying to get her dressed, she's like, quite floppy. I mean, she also has seizures, yeah, and it's quite hard to, like, I mean, I'm not sure how to explain it, but I think it's like absence seizures, but she'll just space off, like she'll just space out basically.	Describes feeding/dressing sister as 'hard' but does she mean physically or emotionally? *Attempts to make sense of the caring relationship in respect to sibling's condition* Says 'I'm not sure how to explain it' but explains well – is she trying to detract from emotional aspect of what she's saying? Is she concerned others won't understand?

	Interviewer: Okay, thank you for sharing that. Can you tell me a bit about your relationship with her? How is that?	
5-Pride in having best relationship with sibling with CMN	Paige: I, like, Moo is, like, my favourite sibling. Yeah, I think me and her are probably, like, the best bond out of the family.	Sibling with complex medical needs is her favourite sibling Love and pride in her sibling relationship?
	Interviewer: What makes you say that?	
6-Sibling's previous abilities now lost 7-Pride in ability to teach sibling when others couldn't	Paige: Because, I mean, when she was younger and she was, like, able to talk and stuff, she was like, with my grandad, she was talking, like, she used to talk to my grandad, well, like, he used to teach her words, but she never used to say them properly, but I was the one that used to teach her all her words. It's really sad to see her lose them all.	Refers to past abilities to explain present relationship *Punctuates speech with 'like'* – is she unsure of herself and what she is saying? Proud of teaching her sister words Sad to see sister's decline
	Interviewer: Yeah, yeah. And what sort of things do you do with Moo?	
8-Description of things she's not allowed to do with sibling 9-Attributes abilities to sibling that she does not have	Paige: We do lots of stuff together, we, well, I'm not really allowed to take her to the shop because, yeah, but I mean, when we're at home, I've tried to teach her how to play hide and seek, like, I've taught Frankie [another sibling] but we sing to her, we sing ABCs and we count to ten. I think she's getting very good at counting to ten.	*Starts by saying they do lots then talks about what they're* ***not*** *allowed to do* Has tried teaching her sister things – implication that she has not learnt Says her sister's 'getting very good' at counting but mum clarifies this
	Interviewer: Great.	
	Paige: Hold on, I'm just going to sit up properly.	Adjusts seating – distraction from topic?
	Parent: She likes it when *you* count to ten, doesn't she?	Parent clarifies that sister likes Paige to count to ten, implying sister is unable to
	Paige: Yeah, she likes it when *I* count ten. She tries to copy.	Reiterates what mum says then adds 'she tries to copy' – holding onto hope that her sister will eventually be able to do this herself?
	Interviewer: Great, and what do you sing to her?	

10-Songs that sibling enjoys	Paige: I like to sing, er, I think it's, erm, 'Row, Row, Row Your Boat'. She likes that one. It makes her smile. But, yeah, [sighs] I like to sing 'Row, Row, Row Your Boat', er and, I can't remember what it's called, 'Wheels on the Bus'. Yeah, they're the kind of songs that she likes.	Explains that 'Row, Row, Row Your Boat' makes her sister smile – this is how she knows she likes it *Filler* – does this indicate nerves? Excitement?
	Interviewer: Excellent. And do you have any particular memories of Moo that stand out to you?	
	Paige: Erm, I'm trying to think. Not really. But…	No particular memories of sister come to mind
11-memory of sister saying her name for first time	Parent: What about the first time she called you Paige?	
	Paige: Oh yeah, the first time she actually said my name. It was, like, really sweet.	Describes first time sister said her name as 'really sweet' – does she genuinely value this? is this mum's memory or hers?
	Interviewer: When was that?	
	Paige: That was when she was, I think, seventeen months, I'm pretty sure.	Uses 'I'm pretty sure' again – is this another instance of uncertainty
	Interviewer: Yeah?	
12-Special bond with sibling	Paige: Yeah. But she said my name out of the whole family first.	Emphasizes special bond she has with sister. Pride?
	Interviewer: Oh wow.	
	Paige: Yeah.	
	Interviewer: That's a real privilege.	
	Paige: Yeah.	
	Interviewer: And could you tell me about your relationship with the rest of your family?	
13-Positive relationship with rest of family	Paige: Erm, we've got quite a good bond, I think. Well, to me it is. But, I get along with my brother a lot. And my sister, yeah.	Emphasizes this is her perspective

	Interviewer: Are they older or younger?	
	Paige: Younger. I'm the oldest.	
	Interviewer: Ah, okay. How old are your brother and sister?	
	Paige: Well, I've got two brothers and one sis…, two sisters, Moo as well. I'm the oldest, then there's Archie, he's 10, yeah. Then there's Imogen and she's 7. Then it's Moo, yeah, and she's 2, nearly 3. Then we've got Frankie and he's 1.	Almost forgets to count Moo as sister – excluded from usual family activities? Describes each of siblings and their ages
	Interviewer: Ah great. Okay, and what do you usually do with them?	
14-Different activities with different siblings 15-Contrast between abilities of sibling with CMN and others	Paige: I like to play… With every sibling there's different things. 'Cause with Archie, I like to play games like on his X-Box and iPad and stuff. With Imogen, we like to go out and play like in the park and that, erm, like football and stuff. Erm, with Moo we like to sing a lot. Singing's the favourite thing. With Frankie, I think his new favourite thing is hide and seek, 'cause he covers himself with my blazer, which is downstairs right now, but he covers himself and then, like, he waits for me to count to 10 and then he runs and hides.	Describes different activities she does with different siblings – <u>is she emphasizing the individuality of each? This seems to highlight Moo's lack of abilities in comparison</u> Sibling younger than Moo has greater abilities than Moo – highlights difficulties
	Interviewer: Ah, okay. Great. And what about your parents? How do you get along with them?	
16-Positive relationship with parent	Paige: Yeah, I get along with my mum a lot. Yeah.	When asked about parents, says she gets along with mum, does not mention dad at this stage
	Interviewer: What do you like to do together?	
17-Preferred activities with mum	Paige: Well, we, I think the funnest thing that me and my mum do is we like to go out to places sometimes. Like, to go eat. Or like, just like, to talk for a long drive.	*'funnest' – highlights how young she is (contrast with previous comments about helping with feeding etc)* Enjoys going out with mum - *Simplicity of activities, time with mum*
	Interviewer: Yeah?	
	Paige: Yeah. With my dad, well, yeah, with my dad, I don't really do a lot with him. But we're	

18-Lack of time spent with parent	more of like a, like a, like kind of, I don't know how to put it, we're like two peas in a pod but we don't really, like, hang out with each other.	Difficulty expressing herself *Metaphor* – does she understand this? Is this a negative? I.e. do they clash?
	Interviewer: Okay.	
	Paige: If that makes sense?	Does it make sense to her?
	Interviewer: Yeah, yeah. So, what, how would you describe a typical day in your family? What does it look like?	
19-Role in getting sibling with CMN ready 20-Emotional impact of caring for sibling with CMN 21-Frequency of appointments 22-Empathy for parent	Paige: I mean, well, I mean, mum wakes everyone up first. She wakes me up first, actually, yeah, but I always lay in. Erm, and then I get up and Archie and Imogen are already up getting dressed for school, and then I get Moo dressed when she's having, like, good days. Erm, I mainly always get Frankie dressed. Erm, but I think it was this morning that I got Moo dressed and she was really, really floppy, and it was really sad to see that, but, erm, I had to just change her into an outfit and do her, do her nappy, and then I did Frankie as well, and we have a lot of doctors' appointments, we have a lot of them, like every, like we've got, like, a lot in a week, and it's quite hard for mum.	Starts and ends response focused on her mum – does she see mum as the glue of the family? Independence of other siblings She gets sister with CMN dress when she's having 'good days' Sister was 'really, really floppy' – describes emotional impact of this *Moves from general to specific instance (this morning) and back to general* Uses 'a lot' three times in quick succession in reference to doctors' appointments – life punctuated by doctors' appointments? Impact on mum – is it hard for her too? Is she protective of mum?
	Interviewer: And do you go along to those?	
	Paige: 'Cause, I went to yesterday's ones, 'cause I had a doctor's appointment, and I went today 'cause I had a doctor's appointment.	*Uses ''cause' three times* Attended siblings' doctor's appointments
	Interviewer: Oh, okay.	
	Paige: But I went into school for the last hour.	Explains that went back to school after appointments – seems to want me to know she did not miss any more school than necessary
	Interviewer: Oh wow. You went to school afterwards?	
	Paige: Yeah.	
	Interviewer: That's great.	

	Paige: Yeah.	
	Interviewer: And do you go to Moo's appointments as well?	
	Paige: Yeah.	Says she attends sibling's appointments but does not expand – perhaps only when necessary, e.g. when she has an appointment too?
	Interviewer: Okay. I'm now going to ask you a bit more about school. So, I take it you're in secondary school?	
	Paige: Yeah.	
	Interviewer: So first I'll ask you about primary school. So, can you just tell me a bit about your time there? What was primary school like for you?	
23-Positive experience of primary school 24-Sadness at having to leave primary school	Paige: I think primary school is probably the best part of, like, going to school. It's definitely the most funnest, and like, I don't know how to put it, but it's like, it's just, I think it's just amazing to go to primary school. But it's really upsetting now I don't go to primary school 'cause I'm in Year 8.	Primary is 'best part' of going to school *Not sure how to express herself* Describes going to primary as 'amazing' – did she have a particularly good experience of primary, or is this in contrast to secondary? Finds it 'upsetting' that she's no longer in primary
	Interviewer: What was so fun about it?	
25-Lack of worry at primary school	Paige: I mean, you make a lot of friends in primary and there's no drama, and there's like, there's nothing to really worry about in primary.	*Uses 2nd person – generalizes her experience* What is upsetting about secondary?
	Interviewer: Yeah? What do you mean, 'there's no drama'?	
26-Relationship issues at secondary school	Paige: [Laughs] In secondary schools, there's mainly drama, like, like falling out of friendships, not getting along with people, people bullying you.	'Drama' in secondary school – relationship issues
	Interviewer: Yeah?	

	Paige: There’s quite a lot of that.	
	Interviewer: Okay. Did you just go to one primary school all the way through?	
	Paige: No.	
	Interviewer: No? Oh right. Tell me about that.	
27-Found large school overwhelming 28-Smaller school is kind and caring	Paige: I went to two. I went to, I think it was, yeah [my first] school, which was, I think, not the best school, it was, like, a really big school. It had lots of children and it was quite, like, overwhelming I guess. But I think in [the second school], it’s, as it’s quite a small school, it’s like, really like, it’s like the whole thing is quite kind and caring, there’s no, like, bullying there or anything. And it’s like a really good school.	First school was ‘not the best’ She found first school overwhelming New school is smaller and she prefers it - it’s ‘kind and caring’ and there’s no bullying
	Interviewer: Why did you change schools?	
29-Needs of other siblings (not the one with CMN)	Paige: I went to [my first school] first, and my brother, who’s got ADHD, he doesn’t like big spaces, or like, lots of people, so since he’s changed, it would just be easier for my mum to just change everyone. So, we all went to [my second school] instead.	Changed school because easier for mum if she went to same school as brother – adapting to family needs
	Interviewer: And would you say you were happier there at [the second school]?	
	Paige: Yeah, yeah, I think it was quite a small and kind school.	Emphasizes new school is small and kind *Uses past tense to refer to current school*
	Interviewer: Great. And what would you say was most memorable for you from primary?	
30-People most memorable about primary 31-Likes going to secondary with people she knew from primary	Paige: I think probably the people there, like, all the friends you make there, and then you go off with them to secondary. I mean, it’s quite, like, nice to know that people you know from primary are going to the secondary school that you’re going to. You know them and you get along with them. And I quite like the teachers as well there.	People are the most memorable thing about secondary school Is having the same people from primary at secondary reassuring/comforting? Likes going to school with people she knows from primary

	Interviewer: Okay. Tell me about them.	
	Paige: Well, I think, when I was there, I'm pretty sure my favourite teacher was probably Miss L, and I think she's still there, isn't she?	*Checks with mum that her favourite teacher is still at primary school*
	Parent: Yes.	
32-Describes favourite teacher at primary providing support	Paige: Yeah, she's still there. Because she used to, like, deal with a lot of stuff when I was there. Like, when I was having bad days, I'd just go to Miss L and she'd sort it.	Liked teacher because she used to 'deal with a lot of stuff' when having 'bad days'
	Interviewer: Okay. And what might have made it a bad day?	
33-Upset when sibling with CMN is not having a good day 34-Difficulty knowing sibling is not having a good day	Paige: Erm, like, I don't know, when Moo's not feeling so good some days, it kind of like upsets me. Then I'll go to Miss L and tell her I'm not having a good day because Moo's not having a good day. And it just upsets me that I know that Moo's not having a good day and it's just not going to be a good day for her and she's like, it's just quite like a hard day when you know that you're sister's like, not, I don't know how to put it, but like, she's not, I don't know the word but she's not…	Sibling being unwell made it 'a bad day' / upsetting Finds comfort in talking to primary teacher *Talks in present tense about going to see teacher at primary even though this is in past* Hard day knowing sister is not having good day *Struggles to express herself*
	Parent: Very well?	*Mum gives her language to explain what she's trying to say*
	Paige: Yeah, she's not very well.	
	Interviewer: Yeah, that's understandable. So that was at primary, this teacher?	
	Paige: Yeah.	
	Interviewer: What about secondary school then? What's your experience been like there?	
35-Relationship issues at first secondary school attended	Paige: I've been to two secondary schools. So, the first one is R, but I don't think it's a very good school. I mean, there's, there's like, constant bullying, there's loads of people, there's like loads of fights there, there's loads of ongoing drama with girls. I mean, if you have	Has been to two secondary schools Describes lots of bullying, fights and 'drama' at first school *Uses 2nd person to generalize experience*

36-New school's approach to bullying 37-School's phone policy	friends from primary, and you go up to them with, erm, secondary like R, you're probably not gonna be friends with them because they're most likely to go off with other people. But the school I'm at now is, like, a really kind school. There's no tolerance of bullying. It's like, it's not strict, but it's got its policies. Like, in R school, you keep your phone but you're not allowed to go on it, but people do 'cause you know, they break rules, but in the school I'm at now, which is H school, which I'm wearing right now [shows badge on blazer], you have to hand in your phone every morning and I think it's really good 'cause then you don't get carried away with social media.	Does the secondary school determine whether you'll remain friends or the people? New school is 'a really kind school' Not strict but has 'policies' – *implies these policies work whereas rules don't* Rules about phones more lax at previous school – is it expected that people break rules? Refers to school uniform – is she proud of this? Prefers new school – can't be on phone
	Interviewer: Yeah? When did you change schools?	
38-Previous school was not good fit	Paige: Well, I went to R school, for a…, I think it was for a year, yeah, and it just wasn't, it wasn't fitting for me, I didn't like it there. Loads of people have moved from there that I know because they didn't like it at all. And then I went into home schooling for about two months, and then we went to more like, I can't remember what they're called, like, when you go to the school, like an appointment, yeah, but we kept going to them with the school, and the more we went to, they were showing us the waiting time and then, basically…	First school wasn't a good fit for her Lots of others have also moved – is it reassuring that she is not the only one with a bad experience? Home schooled for 2 months *Can't remember words* *'yeah' – checking in that I am following?* Has she lost track of the question?
	Parent: You've been there two weeks, haven't you?	Parent interrupts to remind Paige of the question
	Paige: Yeah, I've been there two weeks.	Been at new school for 2 weeks.
	Interviewer: Ah, okay, so you only started there two weeks ago?	
	Paige: Yeah.	
	Interviewer: So, it sounds like it's going well so far?	
39-Making new friends	Paige: Yeah, I've made so many new friends. It's really good.	Lots of friends at new school

	Interviewer: Great. And what subjects do you enjoy?	
	Paige: English, Art, I think it’s English and Art I like. And PE.	*Seems unsure when asked about favourite subjects – ‘I think it’s…’*
	Interviewer: Okay, are you good at those?	
	Paige: Yeah.	*Appears confident in abilities.*
	Interviewer: What would you say is most memorable for you about secondary? I know you’ve been at home, you’ve only just started this school and you’ve been to another school, so you can choose what it is that stands out in your mind when you think about secondary school.	
40-Poor experience of secondary school 41-Values school that meets needs of pupils with SEND 42-Pupils with various needs relate to one another	Paige: I mean, if I’d to put it between R school or H school, if I was thinking about R school, I’d just say it was, like, not a very good school overall. But if I had to pick H school, if I had to choose something about H school, I’d probably put, I mean, it’s a really, really, really good school. Like, there’s loads of people with like, special needs and they take care of them, and people with, like, autism and ADHD and epilepsy and stuff like that. There’s a lot of people there and they all, like, relate to each other. Everyone’s got something. So they’re not all perfect.	*Compares her two schools* Old school ‘not a very good school’ *Repeats ‘really’ 3 times to emphasise how good new school is* Likes that new school ‘takes care’ of pupils with diverse needs Pupils relate to each other – do you need to have SEND to relate to someone else with SEND? Is anyone perfect? What was her experience of special needs at her old school? Recreates home experience at school?
	Interviewer: Okay. It sounds like that’s really important for you. Is it a special school or does it have…?	
	Parent: It’s mainstream but they’ve got a special school attached to them.	
	Paige: It’s a mainstream but they’ve got a special school attached.	Goes to a mainstream school with a special school attached
	Interviewer: I see.	
	Parent: It’s very inclusive, isn’t it?	

	Paige: Yeah, it's very inclusive.	Current school is 'very inclusive' – *this is mum's language*
	Interviewer: Great. Okay, I, I just want you to have a think about having Moo as your sister. Do you feel that that influences…or having Moo as a sister has any influence on how school is for you?	
	Paige: Mmm…	
	Interviewer: So you talked a little bit before about at primary maybe being upset some days and going to a teacher.	
	Paige: Oh, yeah.	
	Interviewer: Does that still happen?	
43-Worry about sibling when not together	Paige: Well, not as much now because I know she's with my mum and, like, she's going to be okay, but it still does worry me that, like, anything could happen to her and I wouldn't know. [Some background noise] You can hear the siblings in the background.	Was she not with mum previously, or is this a more mature understanding? Worries that 'anything' could happen to sister and she wouldn't know while at school – what does she imagine could/might happen?
	Interviewer: [laughs] that's alright.	
44-Worry when sibling when in hospital	Paige: I always worry when they're in hospital. Yeah, I always wonder if she's in hospital, what's happening. And I'm like, it's just, it's nerve-wracking to be honest 'cause I couldn't know what's happening to her 'cause I'm not there and I'm at school.	*Repetition of 'always' – pervasive worry/wonder* *Stumbling over words – reflecting inner turmoil at thought of sister in hospital?* *'to be honest' – she's revealing something about herself that is personal* Doesn't know what's happening to sister because she's at school – does she *blame* school for her not being there?
	Interviewer: Yeah, yeah.	
45-Knock-on effects of sibling's complex medical needs	Paige: It's just quite… And sometimes, like, they're late.	*Changes course* – because parent present, is there something she doesn't want to say? Late – worries increases?
	Interviewer: Sorry, say that last thing again, I missed it.	
	Paige: Sometimes they're late.	

	Interviewer: They're late? Ah, to pick you up?	
	Paige: Yeah.	
	Interviewer: Okay, and what happens then?	
	Paige: [giggles]	*Laughs – doesn't answer question*
	Parent: When have we been late? Oh, we've been late when Moo has had a seizure, haven't we?	
46-Vague memory of sibling having seizure	Paige: I'm just trying to think of like, things that they've been late for. I mean, they were late to pick up, who was it? I can't remember who it was but it was because Moo had a seizure. Like, a really, really long one and she had to go, like, did she go into hospital?	Doesn't seem to be a common occurrence that they are late because struggles to remember but feeling of worry seems to have stayed with her Remembers when mum was late to pick up brother because sibling had seizure *Checks with mum about details*
	Parent: Yeah.	
	Paige: She had to go into hospital. I think it was Archie. Probably Archie. But she was late to come pick up Archie from school and Moo… the reason she was late was because Moo had had a seizure.	Effect of sibling's seizures on others
	Interviewer: And what happened with Archie? Did the teachers take care of him?	
	Paige: Yeah. They, like, do they still do it when they have a little room and they wait for someone else to pick them up?	*Asks mum to confirm details about school*
	Parent: Yeah, they were really good, weren't they. They were like, take your time, mum, we've got him.	Is mum trying to reframe this as a positive experience?
	Paige: Yeah.	
	Interviewer: Good, good. Do you think that what happens at school affects your time with Moo?	

47-Difference between own perspective and other people's	Paige: I wouldn't say it does, but I feel like it does. But from other people's views, I don't think it, like, they don't think it, like, should.	*Contradiction between how it may seem to others and how she perceives it* *Care for sibing permeates her school experience*
	Interviewer: Okay, but I'm interested in what you think, so how do you feel it affects your time with Moo?	
48-Gets comfort from sibling with CMN 49-Bond with sibling with CMN	Paige: Well, I mean, I'm there for, is it six hours? Yeah, I'm there for six hours and for them six hours, I don't see Moo and I'm not sure what's happening, and usually, when I get really upset, I go to Moo, 'cause she knows when I'm upset, 'cause she like, she comes to me but she won't say anything 'cause she can't say anything, but she'll just stand there and look at me, and like, when she looks at me, I know she means, are you okay or whatever, because like I don't know, I think I just, a massive, massive bond with her that I just know what she like, thinks, and stuff. The more time that I think that I'm not there, the more stuff that I could be teaching her but I'm not.	Doesn't like uncertainty Finds comfort in sister *Has 'massive, massive bond' with sister – tries to convey her closeness to sister despite her sister not being able to speak* *Speaks as if to sister* *Reciprocal* Sees role as her sister's teacher – is there any other role she plays in her sister's life?
	Interviewer: Is there any other ways you feel that time at school affects your time with Moo?	
	Paige: Not really, no.	
	Interviewer: Okay. That's really interesting what you've just said. So, thinking about what we've talked about, how would describe your ideal school?	
	Paige: What, like, if I made a school?	Clarifies question
	Interviewer: Yes. If you made a school, what would it be like?	
50-Ideal school would be for pupils with SEND 51-Understands other people's needs better than most	Paige: [Giggles] I think, if I was to make a school, I'd probably make, either a primary school or a nursery school, but I'd make it for people probably with special needs. I feel like I understand people more than, like, how other people do. I don't know how to put that, but I mean like, with Moo, I understand a lot, but she	Would make a primary or nursery for pupils with SNED Insights into children with 'special needs' due to relationship with sibling

	doesn’t say anything, but I know what she wants when, like, she just looks at me.	Feels like she understands people better than others do based on understanding of sister’s needs
	Interviewer: Yeah, yeah. So, that sounds like if you were running a school, that’s the sort of school you would make. What about for siblings like you, what would your ideal school be for them? What would it be like?	
52-Difficulty putting thoughts into words 53-In ideal school, would be able to call sibling	Paige: Well, if I had to put it, the way I like school, I’d probably…I don’t know how to put it…I think that some schools should, like, I don’t know how to put it, if we’re missing our siblings and if they do have special needs, I feel like they should let us call them, or at least like, I don’t know how to put it, but I think they should just let us call them and make sure they’re okay, something like that.	Struggles to articulate herself Thinks siblings should be allowed to call home to check on brother or sister with CMN *Something like that – seems unsure about what she’s just said*
	Interviewer: What about the teachers? What would they be like?	
54-Teachers would have balance between strict and kind 55-Teachers would ask how siblings are but not dig deeper	Paige: I would probably have teachers that are not very strict, but a little bit strict, but they’re kind of like, really kind, I’d probably have them. So, if they wanted, like, they wouldn’t ask, they would ask how your day is, but they wouldn’t ask, like, if you were to say something’s bothering you, they wouldn’t ask what until you tell them what’s going on because they don’t want to invade your space. I’d have teachers like that.	*Teachers would be ‘not very strict, but a little bit’ – looking for a balance* Teachers would ask how your day is but wouldn’t inquire further ‘until you tell them what’s going on’ – doesn’t want teachers to ‘invade your space’ *Satisfied with response*
	Interviewer: And is there any part of your ideal school that’s similar to your current school?	
56-Similarity between current and ideal school 57-Pass to leave class when needed in current and ideal school	Paige: Well, I kind of like, probably, if I was to have my ideal school, like the school I’m in now, they’d give you, like, a little card and it would give you like a pass to chill out if you needed some space and time, or you needed to go on a walk to clear your head. And you can also go and sit down in medical if you really need to, or you can go sit with someone you trust.	*Hesitant* *Likens ideal school to current school* *Moves from talking in conditional to present*
	Interviewer: Is that something that you have?	

	Paige: Yeah.	
	Interviewer: Do all pupils have it?	
58-Boundaries she would impose at ideal school	Paige: You get given it in my school, but if I was to make a school, I'd probably give it to everyone. But if they had made a wrong decision I'd probably take it off of them, like if they was just using it to get out of school.	In ideal school all pupils would have pass to leave class Would impose some sort of boundary
	Interviewer: What led to you getting one of those cards?	
59-Own medical needs	Paige: Because I've got, I don't really know how to explain it but, 'cause I've got epilepsy but it's not controlled.	She has epilepsy
	Interviewer: Ah, okay.	
60-Own emotional needs / possible SEND	Paige: Yeah, I have a lot of issues with my emotions and I'm getting diagnosed with what Archie's got…	Says she is 'getting diagnosed' with ADHD – how has this been conveyed to her? Does she mean being tested?
	Parent: ADHD.	
61-Personality traits (linked to autism) 62-How she manages emotions at school	Paige: Yeah, I'm getting diagnosed with ADHD and maybe Autism. Erm, they think I'm quite like, I don't know how to put it, I'm quite straight-forward. If there's something I don't like I will tell them but other people will kind of like, they'll sit back in their shell. But like, they gave me a card just, like, if I needed space, like, for my emotions, like if I'm angry, like really angry or sad but I don't want to tell them, I can just go for a walk with one of my friends or a teacher. But it's kind of, I don't really use it often 'cause I don't like getting out of school, like I don't use it to get out of school, but I use it when I need it.	Says she is being diagnosed with ADHD and maybe Autism Explains that she is 'quite straight-forward' Explains why she has a card to let her out of class *Emphasises that she would need to be 'really angry' to use card* *Stops mid-sentence* Explains that she only uses card when she needs it – not just to get out of lessons
	Interviewer: Yeah. So, you've got so much insight into the lived experiences of siblings of children with complex medical needs, is there anything you think all schools should do differently to support siblings of children with complex medical needs?	

	Paige: I think, probably, in my old school, R school, they didn't have a lot of first aid people, so I think every school should have at least 3 first aid teachers. Yeah, I did a first aid course.	
	Interviewer: You did a first aid course?	
	Paige: Yeah, but I think they should, like, teach them to do a first aid course.	
	Interviewer: Is that for the siblings or for children with complex medical needs?	
63-Siblings should learn First Aid	Paige: Probably with, yeah, probably with the siblings. They'd teach you first aid things if anything did happen.	Wants siblings to learn First Aid
	Interviewer: Mmm, okay, yeah. Anything else? Things that schools should do differently for siblings of children with complex medical needs?	
64-Pupils with disorders should be allowed toilet pass 65-Teachers don't allow pupils to go to the toilet during lessons	Paige: I was going to say something about the school toilets. [giggles] In mainly all schools, you, like, well, in R school at least, if you was to ask to go to the toilet, mainly they would tell you no, but if you have like a disorder that you can't stop your bladder, I think it would be really handy if you like, get a toilet card, which like, you just show them and they'll let you go to the toilet. Mainly all the teachers in R school stop you from going to the toilet 'cause they think it's a waste of lesson, even though you, like, need the toilet, they won't let you out.	Wants siblings to have a toilet pass to use if they need it Talks hypothetically about children with a 'disorder' that means you 'can't stop your bladder'
	Interviewer: Okay. So a card for pupils who might need to use the toilet during lessons?	
	Paige: Yeah if they have, like, a good reason to, I think, yeah.	Clarifies toilet pass is for pupils who have 'a good reason to' *'I think' – seems unsure/hesitant*
	Interviewer: Is that something you have in your new school?	

	Paige: No, but I don’t need one, but there might be one. I’m not sure about that one, but yeah.	Unsure whether toilet pass exists in new school
	Interviewer: So, thinking about being Moo’s sister, is there anything that you think your school should do differently to support you?	
	Paige: Mm, mm, I don’t know. Erm, I’m not really…	Unsure what school should do differently
	Parent: What about something to do with art? You’ve done art therapy, haven’t you?	
66-Usefulness of art therapy for siblings of children with CMN	Paige: Oh yeah, art therapy. For example, I used to have a private art therapy teacher and it really helps. Like, we used to just sit there and fidget, and play with slime, and like, kinetic sand, and stuff, like art, we used to paint and draw, but I think that’s a really good thing that schools should do.	With parent’s help, remembers how art therapy helped her *In past but uses present – ‘it really helps’* Remembers vividly the art resources ‘used to’ x 3 – *reminiscing* Recommends for schools
	Interviewer: When did you do that?	
	Paige: When I was, I think I was eight, when I used to do it but we had to quit because it’s really expensive.	Unsure of age at the time – ‘*I think I was eight’* Had to stop because of cost
	Interviewer: Yeah. So, did they come to your house?	
67-Positive memories of art therapy	Paige: We used to go to her and she had a shed in her back garden and it was, like, filled with loads of toys and like, there was a massive sandpit. It was really good.	*Uses lots of intensifiers – loads, massive, really to convey excitement/positive memory*
	Interviewer: So, art therapy in school for siblings like you?	
	Paige: Yeah.	
	Interviewer: Sounds great. Is there anything else you want to tell me that I’ve not asked about?	
	Paige: No, not really.	

Appendix Q.

Examples of Emergent Themes by Subordinate Theme

Extract of emergent themes clustered by subordinate theme for Paige:

Friendships at school	**Negative perception of school**	**Difficult peer relationships**	**Benefits of smaller school**	**School policies**	**Pupils with variety of needs**	**Knock-on effect of having sibling with CMN**	**Difference in perception**	**Ideal school for pupils with SEND**	**Rule changes at ideal school**
25-Lack of worry at primary school	38-Previous school was not good fit	26-Relationship issues at secondary school	28-Smaller school is kind and caring	36-New school's approach to bullying	41-Values school that meets needs of pupils with SEND	45-Knock-on effects of sibling's complex medical needs	47-Difference between own perspective and other people's	50-Ideal school would be for pupils with SEND	53-In ideal school, would be able to call sibling
39-Making new friends	40-Poor experience of secondary school	35-Relationship issues at first secondary school attended	29-Change of school due to needs of other siblings (not with CMN)	37-School's phone policy	42-Pupils with various needs relate to one another	46-Vague memory of sibling having seizure		56-Similarity between current and ideal school	57-Pass to leave class when needed in current and ideal school
30-People most memorable about primary			27-Found large secondary school overwhelming						58-Boundaries she would impose at ideal school
31-Likes going to secondary with people she knew from primary									

Extract of emergent themes clustered by subordinate theme for Daisy:

Responsibilities of sibling of child with CMN	**Time spent with sibling with CMN**	**Changes to role with sibling as I grow up**	**Shared interests with dad**	**Lack of time with mum**	**Parents' working patterns**	**Role of sibling's carer**	**Relationship with peers in primary school**	**Positive relationships with teachers**
1-Feeling like a carer	3-Enjoying time with sibling with CMN	5-Changes over time	10-Shared interests with parents	11-Lack of time spent with mum	17-Parents’ working patterns	19-Sibling’s carer	22-Relationships in primary school	23-Liked by teachers in primary
2-Expectations of siblings of children with CMN	4-Time spent with sibling with CMN	6-Previously played more with sibling	13-Daddy’s girl	12-Few memories of time alone with mum		21-Carer provides respite for parents	24-Didn’t relate to peers when younger	32-Memory of good teacher
18-Chores	8-Sibling’s reaction to seeing her after time away	7-Impact of exams and homework		15-Desire for more time with mum				
20-Caring responsibilities	9-Sibling’s perception of time							
	37-Feeling tired from school							

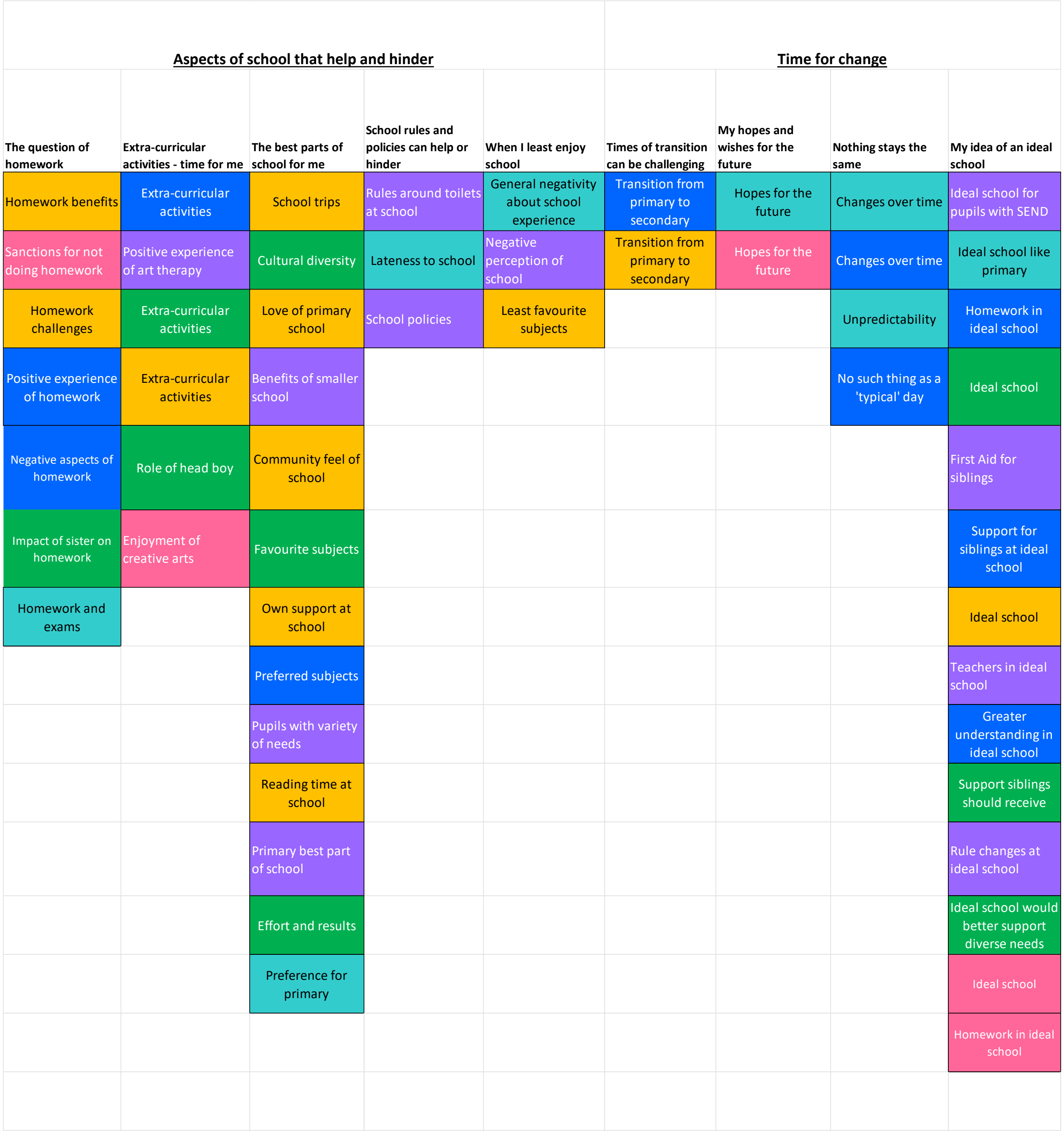
Appendix R.

All Subordinate Themes Grouped by Superordinate and Master Themes

Key:

Paige ■ Zack ■ Anna ■ Mallory ■ Daisy ■ Ella ■

My family life				My growth and development			The importance of relationships at school		
Challenges we face as a family	**Me and my sibilng with CMN**	**Me and my parents**	**Extra help that makes a difference**	**My responsibilities for my sibling with CMN**	**The toll on my wellbeing**	**Learning from my sibling with CMN**	**Teachers can be important**	**The impact of relationships with peers**	**Others don't understand**
Sibling's difficulties	Relationship with sibling	Parents' work	Role of sibling's carer	Additional responsibilities	Impact on sibling of child with CMN	Lessons from my sister	Relationship with teachers are primary	Relationship with peers at primary	Teachers lack understanding of different conditions
Sister's negative experiences at school	Time spent with sibling	Relationship with parents	Supporting factors	Changes to role with sibling as I grow up	Impact of sister's CMN on sleep	Enhanced understanding of other people	Relationship with teachers at secondary	Friendship	Lack of understanding
Sibling's difficulties/ needs	Relationship with sister	Shared interests with dad	Support for sister at school	Increase in responsibility	Impact of CMN on sibling's learning	Being cautious as a result of having sibling with CMN	Relationship with teachers	Friendships at primary	Difference in perception
Sister's CMN	Time spent with sibling with CMN	Relationship with parents	Sibling's carer gives family a break	Responsibilities of sibling of child with CMN	Impact on sleep		Difficulties with teachers	Friendships at school	Need for more compassion
	Feelings towards sibling	Activities enjoyed with family		Responsibilities related to sibling	Emotional impact of having a sibling with CMN		Favourite teacher	Relationship with peers in primary school	
	Relationship with sibling	General family dynamics			Knock-on effect of having sibling with CMN		Positive relationships with teachers	Making friends at secondary	
	Sister's able to stay home alone	Relationship with parents			Uncertainty of sibling's illness		Supportive teachers	Peer relationships at secondary	
		Supportive parents			Own health and wellbeing			Friendships at school	
		Lack of time with mum			Managing emotions at school			Friendships at secondary	
		Relationship with parents			Worry about sister with CMN			Difficult peer relationships	
		Parents' working patterns			Participant's own medical/emotional needs			Witnessing a fight at school	
		Relationship with other siblings			Medical appointments			Negative peer interactions	
		Communication in family						Bullying at school	
		Demands on parent							
		Outings with family							



Aspects of school that help and hinder					Time for change			
The question of homework	**Extra-curricular activities - time for me**	**The best parts of school for me**	**School rules and policies can help or hinder**	**When I least enjoy school**	**Times of transition can be challenging**	**My hopes and wishes for the future**	**Nothing stays the same**	**My idea of an ideal school**
Homework benefits	Extra-curricular activities	School trips	Rules around toilets at school	General negativity about school experience	Transition from primary to secondary	Hopes for the future	Changes over time	Ideal school for pupils with SEND
Sanctions for not doing homework	Positive experience of art therapy	Cultural diversity	Lateness to school	Negative perception of school	Transition from primary to secondary	Hopes for the future	Changes over time	Ideal school like primary
Homework challenges	Extra-curricular activities	Love of primary school	School policies	Least favourite subjects			Unpredictability	Homework in ideal school
Positive experience of homework	Extra-curricular activities	Benefits of smaller school					No such thing as a 'typical' day	Ideal school
Negative aspects of homework	Role of head boy	Community feel of school						First Aid for siblings
Impact of sister on homework	Enjoyment of creative arts	Favourite subjects						Support for siblings at ideal school
Homework and exams		Own support at school						Ideal school
		Preferred subjects						Teachers in ideal school
		Pupils with variety of needs						Greater understanding in ideal school
		Reading time at school						Support siblings should receive
		Primary best part of school						Rule changes at ideal school
		Effort and results						Ideal school would better support diverse needs
		Preference for primary						Ideal school
								Homework in ideal school