The experiences of families of Children and Young People with chronic illness within education

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Abstract

Chronically ill children are an often-overlooked subgroup of the school-aged population. There is a small subsection of research that explores caregivers' experiences of engaging with the education system, but little research on children's school experiences, and even less understanding of what might be influencing their experiences. Caregivers and children who are chronically ill often experience the same event but from different positions, and the experience of one often impacts the other. Therefore, this research sought to explore the perceptions of both children and their caregivers in the hope of developing an understanding of what impacts educational experiences.

This study used Interpretive Phenomenological Analysis (IPA) to explore chronically ill children and their caregivers' experiences of the education system. Two families participated in this research, and six semi-structured interviews were conducted, three with chronically ill children, and three interviews with their caregivers. The children were aged 11-16, currently attending an education setting and had received their diagnosis of their chronic illness at least one year ago. All children had an attendance of below 90% which was perceived by caregivers to be a result of their health condition.

Using the six steps of IPA (Smith et al., 2009), the transcripts were annotated, analysed, and interpreted. Six superordinate themes were identified for caregivers: (a) Collaborating with school, (b) The perceived impact on the child, (c) School isn't for chronically ill children, (d) Despite everything…, (e) The emotional impact, and (f) Hopes, fears and the future. For children, five superordinate themes were noted: (a) The adults around the child, (b) The impact on the child, (c) the role of peers, (d) what is helpful?, and (e) Hopes for the future.

Both caregivers and children noted three key areas that impacted positively on school experiences: Friendships, key adults in school and the benefits of blended learning. Participants noted systemic processes and a perceived lack of understanding as key factors in negative educational experiences.

Summary

This thesis comprises of three distinct parts: a major literature review, an empirical research paper and a critical appraisal of the research.

Part one

Part one is divided into three sections. Section one contains a narrative review of the literature, providing a contextualisation of the literature around children with chronic illnesses. Section two is a systematic style literature review that explores the experiences of education that chronically ill children and their caregivers have. Section three synthesises and discusses all relevant research. The major literature review concludes by presenting the rationale and research questions for part two, the empirical research paper.

Part two

The second part of the thesis is the empirical research paper. An overview of relevant literature pertaining to chronically ill children and their caregivers' experiences of education is provided. This is followed by the chosen methodology, and research design. Six semi-structured interviews were conducted with two families regarding their experiences of education when either chronically ill, or as a caregiver for a chronically ill child. The method of data analysis is detailed, and the themes generated from the data are offered. These themes are then considered in relation to previous literature and psychological theory. Finally, implications for Educational Psychologists practice are offered, alongside possible directions for future research. The empirical research paper concludes by offering strengths and limitations of the current research.

Part three

Part three of the thesis offers a reflective and reflexive account of the major literature review and the empirical paper. A critical lens is taken to the research, and justification is offered for decisions taken as part of the research process. Possible alternative decisions are also spoken to during this part of the thesis.

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This thesis is dedicated to 18-year-old Rachel, who was told she couldn't; this is proof that you could, and you did.

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List of Abbreviations

ALN – Additional Learning needs
ALNET – Additional Learning needs and Education Tribunal act
AN – Anorexia Nervosa
ASSIA – Applied Social Sciences Index and Abstracts
BEI – British Education Index
BPS – British Psychological Society
CASP – Critical Appraisal Skills Program
CI – Chronic Illness
CF – Cystic Fibrosis
DECLO – Designated Education Clinical Lead Officer
DLA – Disability Living Allowance
EHCP – Education and Health Care Plan
ELSAs – Emotional Literacy Support Assistants
EP/EPs – Educational Psychologist/Educational Psychologists
ERIC – Education Resources Information Centre
HCPC – Health Care Professionals Council
IBD – Inflammatory Bowel Disease
IDP – Individual Development Plan
IEP – Individual Education Plan
LA – Local Authority
MMAT – Mixed Methods Appraisal Tool
NHS – National Health Service
PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SANRA – Scale for Assessment of Narrative Review Article

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Chronically ill children and their caregivers' experiences of education: an interpretative phenomenological analysis

Part One: Major Literature Review

Word count: 9728

Part One: Major Literature Review

1. Introduction

Children with chronic illness make up a small but significant number of the school age population. It is difficult to identify the exact number of children with chronic illnesses, with estimates placing the number anywhere between 13 and 31% (Newacheck & Taylor, 1992; Miller et al., 2016). Research has suggested that children with chronic illnesses can perform significantly lower academically than their peers, despite there often being no specific learning or educational need identified (Freckmann et al., 2018). Evidence has suggested that with the right support in place for these children, they are able to perform in line with, or exceed the achievements of their healthy peers (Hilliard et al., 2015). Children with chronic illnesses can find it difficult to share their conditions with their peers, and are at a heightened risk of being ostracised, and developing low self-esteem (Sentenac et al., 2013; Pinquart, 2014). This presents additional challenges for the children to manage, on top of ongoing health needs. The Coronavirus pandemic has furthered the existing disparity between healthy children, and those with chronic illness due to the increased risk the virus posed to their wellbeing (Serlachius et al., 2020).

Research has found that school staff may have anxieties about supporting children with chronic medical conditions, as they fear doing or saying the 'wrong thing' (Prevatt et al., 2000; Gómez et al., 2020). School staff may also hold misconceptions about the child's academic, social, or physical capabilities (Stern & Arenson, 1989). Research has suggested that having a supportive teacher is one of the key aspects of a child with chronic illness excelling in school (Edwards, 2018; Vanclooster et al., 2021).

With the introduction of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 (ALNET; Welsh Government, 2018), there is an increase in the importance of collaborative working with colleagues in health to support the needs of these young people.

1.1 Overview of the literature review

This literature review is split into two sections, as advocated for by Boland et al. (2017). Section one, the narrative section, which will allow for contextualisation of the research, and will synthesise the experiences of chronically ill children and their families. This section will not aim to cover all literature in relation to chronic illness, but instead to provide an overview of the children's experiences, and systems around the children (namely family and school) as well as the wider impact of legislation pertinent to children who are chronically ill. The second section will use the principles of a systematic literature review. This section will aim to explore the current research around the educational experiences of chronically ill children and their caregivers, before identifying common themes throughout the literature. A third section will then discuss the findings from both section one and section two of the literature, finishing with the research questions that will be explored in part two of this thesis.

Section one: Narrative style literature review

1.1. What is a chronic illness or condition?

There are a number of different definitions of chronic illness, and there is ongoing debate in both theory and people's perspectives over what constitutes a chronic illness. This debate centres not only on what illnesses should be included under this term, but how long a patient should have had the condition for it to be considered chronic (Dowrick et al., 2005). More recent debates have also explored whether this phrasing should only denote medical conditions, or whether developmental disorders and conditions such as visual impairment should also be considered chronic conditions (Bernell & Howard, 2016). There is also debate regarding the length of time a person must have a condition for it to be considered chronic. Some definitions suggest this it is three months or longer (Bernell & Howard, 2016), others suggest 12 months as an accurate time frame (Centers for Disease Control and Prevention, 2021), whereas NHS Wales (n.d.) considers a chronic illness to be lifelong, and incurable, only manageable. Whilst a consensus on the terminology has yet to be reached, there is some consistency in the definition used across the research and medical professions. For professionals in education, understanding of what constitutes a medical condition is likely to be provided by other agencies, such as a doctor, or specialist nurse (Lightfoot et al., 1999). In light of these considerations, this research has chosen to use the definition of Wijlaars, Gilbert and Hardelid (2016, p882) to frame their consideration of what a chronic illness is:

'Any health problem requiring clinical follow-up for >12 months... Medical follow-up was defined as repeated hospital admission, specialist follow-up through outpatient department visits or use of support services such as physiotherapy or speech and language therapy.'

The terms 'chronic illness' (O'Brien et al., 2009) and 'chronic condition' (Miller et al., 2016) are used interchangeably throughout the literature, and as such, this will be reflected in the writing of this literature review.

1.2. Prevalence of chronic illness

Chronic health conditions across the whole population are continuing to rise (World Health Organisation, 2022), with a broad estimation that half of Europe's population will be affected by 2025 (European Respiratory Society, 2022). Chronic conditions present significant challenges to healthcare, and account for up to 85% of all deaths in Europe (Stavrou & Demetriou, 2021). There has been some difficulty in accurately identifying the number of children with a chronic illness in the UK, in part due to the inconsistent definitions used to identify children with ongoing medical needs. Depending on the definition used, the prevalence of chronic illness in children has been placed anywhere from 13 – 31% (Newacheck & Taylor, 1992; Miller et al., 2016). The most recent comprehensive assessment was published in 2014/15. The Office for Health Improvement and Disparities (2015) in England found that at the age of 15, 14.1% of the population had been diagnosed with a long-term illness, disability, or medical condition by a doctor. Data in Wales is less succinct, with 5.7% of males, and 4.3% of females aged 0-24 identifying as having a long-term health problem or disability in the 2011 census (Public Health Wales Observatory, 2011). Wales recorded the highest percentage of young people with chronic illnesses when compared to England, in all regions and for both males and female respondents.

1.3. Development of chronic illness in childhood

Research into contributing factors is ongoing, with areas such as lifestyle, adverse experiences, genetic disposition, and individual characteristics being identified as contributing factors to developing a chronic illness (Stavrou & Demetriou, 2021). Glover et al. (2004) suggested that socioeconomic inequality is evident for many major chronic illnesses such as diabetes. Furthermore, Nikiema et al. (2010) suggest that children living in poverty in the United Kingdom in their first year of life are significantly more likely than their economically higher peers to develop a chronic illness by their fourth birthday. Further research is required to understand the links between contributing factors and chronic illness before firmer conclusions can be drawn.

1.4 The educational context of children with chronic illness

Teachers note that following a diagnosis or treatment for an illness, they identify changes in the children's academic, social emotional and behavioural needs (Papadatou et al., 2002). Teachers have identified several difficulties when attempting to integrate children with chronic conditions into the community classroom. These included insufficient school resources to meet the level of need the children have (Seki et al., 2017), the level of absence children with chronic illnesses have (Mukherjee et al., 2000), and staff confidence around meeting the needs of children with a chronic illness (Duggan et al., 2004). Despite these concerns, teachers also reported feeling a sense of responsibility to meet the needs of these children despite limited, or no training on their needs and how best to support them (Clay et al., 2004).

1.5 The Additional learning Needs and Education Tribunal Act (Wales) 2018

The introduction of ALNET (Welsh Government, 2018) has placed a greater emphasis on the needs of children and young people with chronic health conditions, as well as increased collaboration with the National Health Service (NHS) around support and implementation of strategies and provision. ALNET (Welsh Government, 2018) states that a person has Additional Learning Needs (ALN) if they have a

> *'Learning difficulty or disability (whether the learning difficulty or disability arises from a medical condition or otherwise) which calls for additional learning provision. A child of compulsory school age, or person over that age has a learning difficulty or disability if he or she has (a) a significantly greater difficulty in learning than the majority of others of the same age, or (b) has a disability for the purposes of the Equality Act 2010 (c. 15) which prevents or hinders him or her from making use of facilities for education or training of a kind generally provided for others of the same age in mainstream maintained schools or mainstream institutions in the further education sector.'* (Welsh Government, 2018, p. 7)

Children with chronic health conditions may meet the definition of ALN as quoted above due to ongoing health needs or absences from school which may lead to gaps in their learning (Irwin & Elam, 2011).

Furthermore, ALNET outlines that in cases where the child's additional learning needs are directly related to a health condition, the NHS should *'consider whether there is a treatment or service that is likely to be of benefit to addressing the learners ALN and, if so, secure that treatment or service'* (Welsh Government, 2018, p. 23) laying out a legal requirement that adjustments and interventions are put in place to support the child's learning. ALNET (Welsh Government, 2018) also legislates the introduction of a Designated Education Clinical Lead

Officer (DECLO) whose role is to oversee and coordinate the local health board approaches to meeting the needs of children and young people with ALN. Crucially, this places a focus on a more coherent, collaborative approach to meeting the needs of children with chronic health conditions (Welsh Government, 2018). Historically, there have been a number of criticisms of the lack of collaboration between health and education when considering the needs of children and young people (Milbourne et al., 2003). Children are often sent back to school with a lack of a health care plan, with teachers and parents advocating for specialist training from medical professionals (Clay et al., 2004), or the placement of a permanent school nurse to meet children's needs (Stavrou & Demetriou, 2021). Similarly, the Children's Commissioner for Wales has highlighted that regional collaboration is needed to ensure that children with complex conditions have their needs met collaboratively, rather than being passed from service to service (Children's Commissioner for Wales, 2020). It would appear that ALNET (2018) seeks to rectify these concerns. Implementation of these policies are still underway, and future research on its impact would be beneficial.

1.6 Additional legislation relevant to chronically ill children

The Governments in England and Wales have specifically noted children with chronic illnesses in several legislation documents, suggesting that there is not just a moral obligation (Unicef, 1989) to meet the needs of these children, but a legal requirement too. The Children and Families Act (UK Government, 2014, p100) makes specific reference to schools having a *'duty to support pupils with medical conditions.'* Similarly, the Equality Act (2010) section E is entirely devoted to the experiences of children with disabilities or chronic conditions. For both England and Wales, there is statutory guidance regarding children's right to an education. In Wales, the Education Act (UK Government, 2002) makes specific reference to local authorities and governing bodies having a duty to ensure that arrangements are made to promote the welfare and safeguarding of children, including those with health needs. The Children's Act (UK Government, 2004) references schools needing to promote physical and mental health, emotional wellbeing, and education. In England, the UK Government (2013) have published statutory guidance on supporting children who cannot attend school due to health needs, and OFSTED (2022) have moved to include reference to chronically ill children in their new inspection framework guidance. In short, children with chronic illnesses' right to education is clearly enshrined in law.

1.7. Summary of section one

Section one of this major literature review set out to provide contextualisation and a broader context of the experiences of chronically ill children and their caregivers. Chronic illnesses are becoming increasingly prevalent in the population, with literature suggesting up to 31% of children may have at least one condition that meets the definition of chronic illness (Miller et al., 2016). Children with chronic illnesses are likely to experience poorer social, emotional, and academic outcomes than their healthy peers (Lum et al., 2019b), and are more likely to receive a psychiatric diagnosis (LeBlanc et al., 2003), not complete vocational education (Gledhill et al., 2000), and be in receipt of government financial support as adults (Maslow et al., 2011).

Outside of the family, teachers of children with a chronic illness often noted their lack of training around managing the child's condition (Duggan et al., 2004), insufficient resources to meet the child's needs (Seki et al., 2017), and the level of absence the child has experienced (Mukherjee et al., 2000) as being barriers to education. The rights of chronically ill children to receive an education are enshrined in law (Children and Families Act, 2004; Equality Act 2010; ALNET, 2018) and are noted as an area of exploration in OFSTED (2002) guidance, highlighting a need for school staff to develop their understanding and to implement appropriate intervention or adaptations.

Section two: Systematic style literature review

The aim of this systematic style literature review was to (1) identify the needs and experiences of children with chronic illnesses and schooling, and (2) the experiences of their caregivers in supporting their child through this experience.

1. Method

1.1. Design

A systematic search was conducted. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2015) were followed, and are shown in figure 1.

1.2. Inclusion/exclusion criteria

The inclusion and exclusion criteria are identified in table 1.

Table 1

The Inclusion and Exclusion Criteria for the Systemic style Literature Review

Inclusion Criteria	Exclusion Criteria	Rationale
The research: ● Examined the views of caregivers or children/young people with explicit reference to school ● The young people concerned were aged 18 years old or younger ● There was a comparative experience to the UK of educational/medical experiences	The research: ● Sought the views of teachers only ● Sought the views of medical professionals only ● Examined the impact on siblings' education ● Examined school-based interventions for children with chronic conditions ● Education was used in a different way e.g. educating nurses on the experiences of chronically ill children	● The views of children and caregivers are what this research intends to explore – the sole views of other individuals are not appropriate to include in this section ● The age of 18 is the highest age of compulsory age of local authority run education in the United Kingdom (Menter et al., 2015)

● The studies were published after 2000	● Focused on the medical management of the condition during education, with no reference to more general educational experiences	● When conducting a systematic style literature review, it is important it is of relevance to the local population (Singh, 2013) ● A cut-off date was provided in an attempt to include studies within recent educational reforms

1.3. Search methods

The search of the databases Education Resources Information Center (ERIC), British Education Index, Applied Social Sciences Index and Abstracts (ASSIA), PsychInfo, Scopus and Medline were conducted from January 2021 to January 2022. One further article was added in March 2022 following a cursory check of the literature. These databases were utilised as they encompass the areas of relevance to this search: psychology, education, and medicine. Search terms included "Chronically ill", "Children", "experiences", "education", "caregiver" and "school." Truncated terms were used to ensure inclusion of all relevant articles. See Appendix A for full search terms utilised. A process of reference list harvesting helped to identify additional sources. Search engines such as Google and Google Scholar were used to identify additional papers – papers included from this search were noted to be peer reviewed. This review focused on papers that were available in English, and that were published from 2000 onwards to ensure relevant and contemporary papers on the experiences of school children and their caregivers were accessed. A range of literature was identified, including peer reviewed articles and doctoral theses.

1.4. Search outcomes

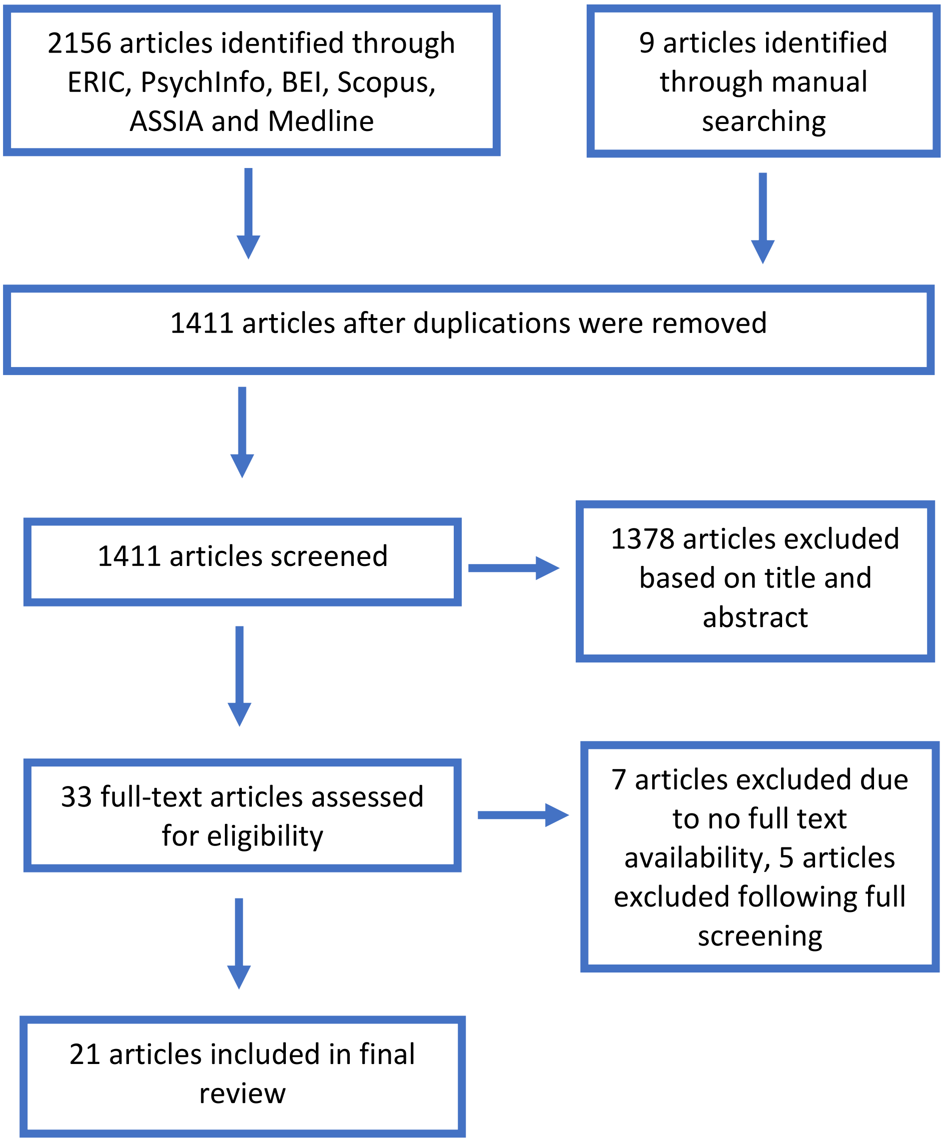
2156 articles were identified using the above methods. Following the removal of duplicate articles, 1411 articles were screened against the inclusion criteria identified in table 1. The screening process is detailed in Figure 1. Five articles were excluded following full screening due to not meeting the inclusion/exclusion criteria. The final 21 articles can be seen in table 2.

1.5. The use of aid memoires

The Critical Appraisal Skills Programme (CASP) was utilised to evaluate qualitative research (Singh, 2013). The Mixed Methods Appraisal Tool (MMAT) was utilised for mixed-methods and quantitative research (Hong et al., 2018). For narrative reviews, the Scale for Assessment of Narrative Review Articles (SANRA) was used (Baethge et al., 2019). These tools were utilised to support the researcher in critically analysing the research.

Figure 1

Flow chart of PRISMA article screening process



2. Results of systematic review

2.1. Characteristics of the studies

This review included 21 research papers that examined the educational experiences and needs of children with chronic illness, and/or the experiences and needs of their primary caregiver. Studies were conducted in the United States (n=6), Belgium (n=4) Australia (n=3), the United Kingdom (n=2), Canada (n=1) and Germany and Austria (n=1). The remaining research consisted of systematic, narrative, or meta-analysis reviews (n=4).
Qualitative studies consisted of semi-structured interviews (n=9) whilst quantitative studies utilised questionnaires (n=5), three articles used mixed-method approaches, with the remaining articles consisting of literature reviews.

Sample sizes ranged from 5 – 675 participants. Most studies identified participants from the most prevalent childhood chronic illnesses in their country and included participants with a range of conditions (N=15) Some studies focused on specific conditions including brain tumours (N=3), Inflammatory Bowel Disease (N=1) and sickle cell disease (N=2). The studies were diverse in the conditions they included, but the homogeneity of the papers is through the exploration of educational experiences for caregivers of chronically ill children, chronically ill children, or both.

The table below outlines the methodologies, findings, and critiques of the papers.

Table 2

An Overview of the Key Papers Identified in the Systematic style Literature Search

#	Author	Year	Country of study	Participants (N): descriptive data provided	Study design	Summary of results	Criticisms
1	Hopkins. F & Gallo. A	2012	United States of America	Parents: N=41 No children participated. Descriptive data Childrens' medical conditions: sickle cell disease (n=25) or cystic fibrosis (n=16) Childrens' demographics: None provided	Secondary data examination of semi structured interviews originally examining family management style. A constant comparative method was used to theme responses.	Four sub themes identified with regards to school 'communication between mothers and the school system,' 'resources provided to child attending school,' 'specific parental concerns regarding their child and school' and 'confidence in school personnel.' Parents tended to use open communication. There were mixed results with regards to the resources used to support the young person and whether families chose to use them. Mothers reported concerns regarding the impact of illness on attainment, friendships, and safety.	A secondary analysis of data that was originally focused on management of chronic illnesses and semi-structured interviews were conducted with this in mind rather than the educational experiences. Researchers coded the transcripts and did not have access to the original recordings. Focused on only the oldest child in the family and excluded adopted children. This research only gathered parental views. Descriptive data was not provided making it difficult to draw conclusions on the impact of demographics such as age or length of time with condition.
2	Boonen. H & Petry. K	2011	Belgium	Parents: N=60. Children: N=60 Descriptive data Childrens' medical conditions: psychological	Questionnaires were sent to both children and their caregivers, examining their experiences of school absence, online learning, and reintegration into school. Participants were recruited via school. Analysis was	Both children and caregivers evaluated home learning as positive. Almost all children were provided with a means of keeping in contact with their peers, and stated they felt part of their class. Caregivers and children were positive about school re-entry, though no measurement of academic achievement or social integration were carried out. Over half of children received some form of support when returning to	Data was gathered via questionnaires which consisted of mainly closed questions, providing no opportunity for participants to expand on their views. Inconsistent data scales were used such as three point and five-point Likert scales as well as multiple choice

				disorder (n=4), a type of inflammation (n=9), a fracture or bone disorder (n=9) a disease relating to immunity (n=11), cancer (n-14) or an undisclosed illness (n=13) Childrens' demographics: age: Mean age of 14 years, Range of 7-19 years.	performed at an individual item level, with frequencies and measures of central tendency and disposition calculated. Pairwise deletion was used for missing data. Closed question data gathering was used. Space for open answers was also provided in some questions.	school. Caregivers believed that homebound instruction stimulated development of their child but were divided on whether it impacted on social contact with peers.	which can be less effective in terms of clarity and statistical analysis. A lack of statistical power was noted, due to the limited sample size. Experiences were considered overall, rather than in subgroups of medical condition. Some participants were noted to have fractures, which may not meet the definition of a chronic illness. Similarly, for those that did not disclose their condition, it may be difficult to consider the impact of their condition on home learning and reintegration.
3	Bowtell. E. C., Aroni. R., Green. G. & Sawyer. S. M.	2018	Australia	Parents: N=38. No children participated. Descriptive data Childrens' medical conditions: Cystic Fibrosis (n=16) Anorexia Nervosa (n=11) and cancer (n=11). Childrens' demographics: N=38 attending upper secondary school.	Semi-structured interviews with parents. Parents were identified through hospitals providing treatment to the adolescents. Data was collected until theoretical saturation was reached. Grounded theory was used to identify themes.	Four themes were identified. 'Keeping life normal by linking health with school-based support,' 'accessing tailored supports as strategies for normal living,' 'managing risk by protecting identity through non-disclosure, secrecy and misdirection' and 'managing the process of disclosure at the health-education interface.' Parents believed continued involvement in education as key to maintaining normalcy and providing better support. Parents suggested that informed educators would provide tailored support and a safe environment both for academic progression and preservation of peer relationships. Parents did however feel that staff had a lack of awareness and engagement in further training. For adolescents with Anorexia Nervosa and Cystic Fibrosis, parents 'edited' the truth for school to avoid stigma, whilst some	This research only gathered parental views. Limited demographics on the young people are gathered, making the generalisability of findings difficult. The relationship between the researcher, participants and the data could have been explored further – referencing potential bias and management of any ethical concerns that emerged during interview.

						didn’t disclose at all due to lack of faith in the school to provide support.	
4	Bruce. B.S., Chapman. A., MacDonald. A. & Newcombe. J.	2008	Canada	Parents: N=16. Children: N=14. Two young adults post education also contributed their views. <u>Descriptive data</u> Childrens’ medical conditions: Children and young adults had a primary diagnosis of a brain tumour (N=16). Childrens’ demographics: Average age of 12.8. Age range 7-20.	Participants were recruited via their medical teams. Individual semi-structured interviews were conducted. Naturalistic inquiry using thematic analysis was used to analyse the data.	Data was categorizable in two key areas: academic difficulties and social difficulties. For young people, being misunderstood by both staff and pupils was a key difficulty, which also lead to academic difficulties as well as the challenges of developing and maintaining friendships. For caregivers, they would seek support that would provide long-term success for the children. Relationship building for social and academic success was also noted as important. The children sought additional resources within and outside of school. Both parents and children felt that generally school lacked the resources to address their needs, though this was alleviated by good coworking between parents and teachers.	The researchers do not explore ethical considerations of the research, or how they might respond to any issues arising during interview. No justification is given for the research design. There is a wide range of experiences which may make the generalisability difficult – some participants are remembering events following a significant period. No explanation for the inclusion of the young adults is given. The researchers have not identified any limitations themselves. No reference is made to the relationship between researcher and participants.
5	Dyson. S. M., Atkin. K., Culley. L. A., Dyson. S. E. & Evans H.	2011	United Kingdom (England)	No parents participated. Children: N=40 <u>Descriptive data</u> Childrens’ medical conditions: Sickle Cell disease (N=40)	Participants were recruited via local support groups, counselling centres and outpatient clinics. 15 interviews were opportunistic sampling. Subsequent sampling was targeted to identify positive experiences (n=15) the remaining 10	20 themes were identified, categorised under four main headings. (1) The field of the clinic (health behaviour deemed necessary to maintain good health challenges to implement them), (2) The field of the school (school absences, school re-entry, catching up on lessons and seeking support), (3) the habitus of the young person with Sickle Cell Disease (managing interpersonal relationships at school) and (4) contextual factors including the role of the mother,	Wide range of ages making it difficult to generalise the experiences – some participants are also no longer in school. This research focused on one medical condition only making generalisability of experiences difficult.

				Childrens' demographics: ages: 5-10 (n=2); 11-18 (n=30); 19-25 (n=8)	participants were recruited from questionnaires, choosing 2 participants from each rating point on a question about school support. Thematic analysis of results was carried out using Bourdieu's notion of field, capital, and habitus.	the potential for sickle cell to be a drain on participants responses, and innovations attempted by the school. Medical advice was not always followed by schools, and pupils often reported being punished for following this. Distress was often minimised by teachers, and academic achievement underestimated. Pupils also reported peer exclusion, and lack of understanding. Mothers were highlighted as particularly important for advocating on behalf of the pupil.	No reference is made to the relationship between researcher and participants. Focus on support from mothers, with no consideration given to families without mothers.
6	Marks, L. A., Wilson, N. J., Blyth, S. & Johnston, C.	2021	Australia	Parents: N=14 No children participated. <u>Descriptive data</u> Childrens' medical conditions: insulin dependent [condition] (N=14) Childrens' demographics: School grade: preschool (n=3), grade 1 (n=7) grade 2 (n=4)	Mothers were recruited via Facebook support groups. Phone interviews were conducted due to geographical spread. Semi-structured interview schedule and open questioning were used. A narrative analysis was used to interpret interview data.	Nine narrative threads under two overarching headings were identified. These were (A) Facilitators of intensive insulin therapy in the early primary school setting with the sub themes of (1) collaborative partnership between parents and school staff, (2) [condition] education: parent or nurse, (3) reasonable adjustments for integrated care, and (4) continuous glucose monitoring system. (B) Implications of intensive insulin therapy in the early primary school setting for mothers with the subheadings of (1) the stigma of advocating, (2) worried about safety in others care, (3) restricted employment, (4) wanting their child to be like everyone else and (5) providing 24/7 care behind the scenes. Whilst some mothers recognised that schools were doing what they could, on the whole there was distrust that school staff understood the severity of [condition], and a lack of confidence with regards to meeting the needs of the child. Mothers highlighted concern with regards to how they were viewed by the school when advocating for their child.	This research only considered maternal experiences. No fathers participated. Childrens views were not considered. Participants were recruited from social media only, excluding those who do not use this form media. Interviews were conducted via phone calls, potentially excluding helpful non-verbal information. The researchers only included year groups and not ages making it difficult to generalise the findings outside of Australia due to differences in school years. No reference is made to the relationship between researcher and participants.

7	Vanclooster, S., Bilsen, J., Peremans, L., Van Der Werff Ten Bosch, J., Laureys, G., Paquier, P., & Jansen, A.	2019	Belgium	No parent participants. Children: N=5 <u>Descriptive data</u> Childrens' medical conditions: Brain tumour (N=5) Childrens' demographics: Average age: 10, range 7-10.	Part of a case study that interviewed children, parents, teachers and healthcare professionals. Semi structured interviews were conducted at school, and were conducted at 0 years, 1 year and 2 years. Participants were in remission and had been reintegrated into school. Inductive thematic analysis was used to explore individual experiences.	Data was categorised under 4 main themes: (1) school life and participation, (2) peer relations and friendships, (3) performance and difficulties, and (4) support and follow up. Children were happy about returning to school; however, participation was challenging, and negatively affected the children when they found it difficult to participate in certain activities. Peer relationships were described as difficult initially but did improve with time. Processing difficulties affected academic work, and there were mixed result regarding satisfaction with progress. Children identified support from parents and teachers as key, though found it difficult to accept they were different to their peers.	The time off school the children had varied greatly (2-33 months) which may impact the generalisability of the findings. Children re-entered education at various point prior to the interviews, and this may have influenced their personal readjustment to schooling. No reference is made to the relationship between researcher and participants.
8	Freckmann, M., Seipp, A., Laass, M. W., Koletzko, S., ClaBen, M., Ballauff, A., Peploes, J., & Timmer, A.	2018	Germany and Austria	Parents: N=675 Children: N=675. <u>Descriptive data</u> Childrens' medical conditions: Crohn's disease (n=404), ulcerative colitis (n=208), or unclassified Inflammatory Bowel Disease (n=63). Childrens' demographics: median age of 14, range of 10-15 years old.	Questionnaires were sent to families via IBD mailing lists. Questionnaires included the CHC-SUN, as well as open response questions. Statistical analysis was conducted, and descriptive statistics were harvested from the results.	Overall children felt they had got along reasonably or very well at school recently (n=555). 42.2% of parents felt that their child's schooling was not impacted by their IBD, with 42.7% feeling that it occasionally caused issues, however 36.7% of parents reported that they felt their child was developmentally behind their peers. 14.1% of children had not disclosed to anyone at school they had IBD, with 46.8% sharing certain aspects of information, or only letting trusted people know. 38.5% were completely open with school and peers regarding their need. The school satisfaction domain of the CHC-SUN was the lowest scored for 40% of participants – there was clear correlation between school satisfaction and academic performance. Open response questions indicated that for some children, they were actively discriminated against due to their medical conditions, and for others they had difficulty engaging socially due to anxiety regarding	Parental and child experiences did not always match – e.g., 555 children stated they were having positive school experiences, whilst 386 parents reported IBD negatively impacting their child's school experience. These disparities were not explored further in the discussion nor linked to literature, which may have been a beneficial point of investigation. The risk of nonresponse bias is not addressed in the research. The research did not compare the results to healthy controls, and reports of absence or repeating grades was not independently verified.

						their medical condition. References were also made to lack of care by school staff. Statistical analysis suggested that socioeconomic status, female sex, and region of residency predicted good attainment in school. Severe disease impacted on the risk of grade retention, but did not predict the type of school attended, nor school marks.	
9	Hoffman, H., Geisthardt, c., & Sucharski, H.	2019	United States of America	Parents: N=31 Young people: N=22 <u>Descriptive data</u> Childrens' medical conditions: N=53 MS. Childrens' demographics: Children of parental participants': mean age 17.6, range 11-33. Young peoples': Mean age 20.6, range 18- 36.	Parents of children with MS were recruited from a larger study of 42 parents of children with MS – these participants were included as their child was college age, or they had expressed specific concerns regarding college for their child. Semi-structured phone interviews were conducted. Individuals with MS were recruited from departments supporting students with disabilities. Participants completed an online questionnaire consisting of open questions and Likert rating scale questions. Thematic analysis was used for both parts of the study. Descriptive statistics were also provided for the Likert scale questions.	Parental interviews identified 4 key themes: (1) Increased understanding of MS by educators is needed, (2) Medical needs, (3) Meeting college demands, and (4) Future employment. Parents felt that a lack of understanding of MS correlated with a lack of support. Where school staff had prior experience of MS in their personal life, significant extra effort was utilised to support pupils. Consideration to daily medical management, as well as location of specialist support was also discussed as well as how the child might consider relapses away from home. Parents worried about children finding a balance between enjoying themselves, succeeding academically and managing their medical needs. Parents also discussed how children were having to alter their ambitions and expectations in light of diagnosis. Individuals with MS considered when and how they disclosed their condition to others, with the majority choosing to disclose immediately. Individuals felt that their college experience was made more difficult by MS, with balancing needs and the knowledge of others reported as the top issues. Participants also reported helpful coping strategies (sleep, listening to music, talking with friends/family), as well as what support was available to them (student disability	Interviews were conducted by phone, meaning it might have been difficult to ascertain non-verbal cues, or invitations to ask further questions. Inconsistent data gathering was used – for part one interviews were used, and for part two questionnaires were used making it difficult to compare results. The rationale for this was not clear. Participants did not appear to be parent/child participants, making comparisons of experiences difficult. Age ranges were wide, making comparisons and generalisability of experiences difficult. For the young people participating, many will be remembering experiences that happened a significant time ago. The research references the parents being part of a large study but does not make it clear whether the data is secondary data from

						service, health services and counselling services), as well as what they would like to have available to them (support group, resources for educating others).	this study, or whether participants completed new interviews specifically looking at the research question.
10	Kliebenstein, M. A., & Broome, M. E.	2000	United States of America	Parents: N=21 Professionals: N=24 (teachers = 8, teachers aids = 3, guidance counsellors = 5, school nurse = 5, psychologists = 3) No child participants. <u>Descriptive data</u> Childrens' medical conditions: [condition] (n=7), GI disorders (n=5), pulmonary disorders (n=3), cancer (n=2). Childrens' demographics: Age: range 5-15 years.	Clinic nurses identified eligible participants and wrote to them regarding the study. Semi-structured, telephone interviews were conducted with parents. Questionnaires were sent to staff. Content analysis was used on all responses to identify recurrent themes.	Five key themes were identified during analysis: (1) sharing the news, (2) making the transition, (3) watching the child, (4) teaching the teachers, and (5) working with the child. Parents felt that school should be informed as soon as possible, despite reluctance from children. School personnel felt that the family should work with key individuals in the school prior to reintegration. Parents felt that school tried to make reintegration positive and were 'somewhat prepared' for the return of the pupil, whereas school staff felt unprepared and uncomfortable with their role. Both parents and school felt it was important to work collaboratively to share knowledge on the condition and the needs of the child. School staff expressed concern around how to engage pupils, as well as how to challenge them academically when faced with a desire to 'mother' the pupil.	Children's views were not sought during this research which may have been helpful given the topic. Inconsistent data collection methods were used. No justification was given for these choices, and no example questions were provided. There is no reference to how the data was recorded. Data analysis is not spoken to in sufficient detail, and the credibility of the findings are not considered. The recruitment process is not clear. Reference is made to a clinical nurse sending out invites, but no further context is given. The relationship between the researcher and participants is not spoken to. There is no reference to ethical issues or considerations.
11	Irwin, M. K.	2013	United States of America	Parents: N=5. Children: N=5. Teachers: N=5. <u>Descriptive data</u>	Patients recruited as part of a wider study. Semi-structured interviews were recorded. An inductive approach was used as the data analysis method.	Five overarching themes were identified during data analysis: (1) Premorbid functioning, (2) Extra support, (3) Change, (4) Missing out, and (5) Implications. Conflicting information seemed to be provided by participants. They denied that there would be any social or academic effects in the short or long term,	This was a pilot study; however, significant detail is provided on the longitudinal research which can be confusing. Due to conflicting reports from participants, further investigation,

				Childrens' medical conditions: tumour (n=3) or cancer (n=2) diagnosis. Descriptive demographics: Age range: 6-10.		yet further explorative questioning identified contradicting statements, where pupils, parents and teachers could give evidence or examples of the impacts of their social and academic needs. It was suggested that the impact of missing academic and social events can be mitigated by extra support from peers, caregivers, and teachers, particularly if there was premorbid success.	such as direct observation, may have been helpful. Three (out of five) of the teacher respondents indicated they had very limited/no relationship with the pupil. Explanation of the recruitment process was not clear. Did not include the quantitative portion of the research. The relationship between participants and the researcher is not spoken to, nor are ethical considerations noted.
12	Runions, K. C., Vithiatharan, R., Hancock, K., Lin, A., Brennan-Jones, C. G., Gray, C., & Payne, D.	2020	Narrative review	38 articles reviewed on Type 1 [condition], Cystic Fibrosis and Hearing Loss	Literature search in PubMed and ScienceDirect. Three separate searches conducted.	Three key themes regarding the impact of chronic illness on mental health were identified (1) Absenteeism, (2) peer relationships: Challenges and opportunities, and (3) Teacher roles and relationships. Absenteeism was found to impact on academic and social functioning. Children reported that acceptance by peers had a positive impact on the mental health of pupils. Conversely, feeling different, stigmatisation and bullying from peers poorly impacted the mental health of chronically unwell school children. A poor relationship with teachers indicated poor psychological adjustment, and poor peer relationships. Similarly, some pupils reported poor adherence to medical treatment due to poor teacher-pupil relationships.	Aims of the research were not fully clear within the review. Explicit research questions may have been helpful. An overview of the included articles and their findings would have been helpful. Explanation of the analysis of the literature and how the areas were identified was also missing.

13	Dyson, S. M., Atkin, K., Culley, L. A., & Dyson, S. E.	2007	Narrative Review	No clear inclusion/exclusion criteria. ‘Commentary on the literature’	N/A	The commentary identified that children with sickle cell often underperform academically and feel un-supported by school staff. The paper identified steps that can be taken to mitigate the impact of sickle cell disease on the individuals including adaptations to the school day, early communication with staff and peers, and using sickle cell for PSHE education.	This research is presented as a commentary on the existing literature, however, no clear inclusion/exclusion criteria and no search process is indicated or included. No research question or hypothesis is offered. Justifications for themes is also not noted.
14	Edwards, K.	2018	United States of America	Parents: N=10. No child participants. <u>Descriptive data</u> Childrens’ medical condition: Asthma (n=1), ADHD, ASD, digestive disorders, leukaemia (n=2), Allergies, scoliosis (n=1) and [condition] (n=1) or several of the above conditions (n=5). Childrens’ demographics: Ages: range 6-15 years.	Participants were purposefully sampled initially, through their relationship with the researcher. Further participants recruited through snowballing. Interviews were conducted in a location of the participants choosing. Interviews were semi-structured and recorded. Prior to the interview, parents completed the Adapted Illness Intrusiveness Rating Scale. Systematic analysis of data was carried out.	Identified themes were (A) supports need of the child with the subthemes of (1) physical, (2) social, (3) behavioural and (4) cognitive. The same subthemes were used for the subordinate themes of (B) support provided to the child and (c) mismatch between child’s functioning & demands inherent to school participation. (D) quality of outcomes had the subthemes of (1) academic progress, (2) school participation and (3) social, growth and experiences. The final overarching theme was (E) collaboration and communication which rather than having subthemes, examined the impact of collaboration between the primary healthcare provider, the child and family and school, and the impact this has on the overarching themes of A & B. Parents preferred having daily communication with teachers, and that this took the form of phone calls or email. Parents had concerns about teachers’ abilities to meet their child’s needs and felt that there was a lack of understanding on the teacher’s behalf. Parents did note that most teachers did have a positive attitude, and a willingness to try. Parents identified that having adaptations to the school day was	Maternal participants only, it may have been helpful to consider paternal views. Children’s experiences were not sought. Justification for method of data collection is not spoken to. Recruitment strategy is explained; participants were known to the researcher. No inclusion/exclusion criteria are noted. The possible difficulties of the participant relationship are not explored. A concept map is offered, as was stages of data analysis, but explanation of how the concepts/themes were arrived at is not clear.

						important to meet medical needs, but also to reduce the chance of negative attention from peers. Understanding from parents, peers and school staff was highlighted as key. Parents perceived advocacy as being important to meeting the needs of the child.	
15	Lum, A., Wakefield, C. E., Donnan, B., Burns, M. A., Fardell, J. E., Jaffe, A., Kasparian, N. A., Kenedy, S. E., Leach, S. T., Lemberg, D. A., & Marshall, G. M.	2019	Australia	Parents: N=400. n= 192 chronic illness group, n=208 control group. No children participated <u>Descriptive data</u> Childrens' medical conditions n=64 with cancer, n=48 with gastrointestinal disease, n=36 with cystic fibrosis, n=26 with asthma, n=12 with kidney disease and n=6 with heart disease. Childrens' demographics: Ages: Average age in chronic illness group 12.10, average age in control group 11.77. age range 5-19.	Caregivers of chronically ill children were purposefully sampled from 4 different locations including databases, outpatient clinics, parent groups and social media. The control group were recruited from a database held by a online survey company. Participants completed a questionnaire that took approximately 30 minutes to complete. Logistic regression was used to analyse the data.	Students with chronic illness were 3.8 times more likely to have to repeat a year of schooling, parents were 3.6 times more likely to report academic challenges, and the children were 4.9 times more likely to have had a recent absence from school due to illness than their healthy peers. Parents of the chronically ill children reported high emotional stress more than 2.2. times that of the control group and were more than 4.6 times more likely to report low social confidence in their children than parents of healthy peers. Children with chronic illness were no more likely than their peers to receive school based or home-based tutoring, nor were they more likely to receive assistance from staff in school.	Children in the chronic illness category were only eligible if they had an illness associated with the highest rate of absenteeism, which may mean results are not generalisable to pupils with chronic illnesses, but better attendance. The views of children were not sought. Large age range – it might make it difficult for the results to be generalisable. Some responses were yes/no answers – it would have been helpful for contextualising information to be provided. There is no consideration of whether the sample size is representative of the general population. The research did not control for the phase of illness (e.g., well, in a flare up of their condition, in hospital) and how this might have influenced the responses.

16	Lum, A., Wakefield, C. E., Donnan, B., Burns, M. A., Fardell, J. E., & Marshall, G. M.	2017	N/A	Systematic Meta-review on the experiences of school aged children, adolescents, or adults with childhood onset illness providing retrospective accounts.	Seven databases searched (CINAHL, Cochrane reviews, EMBASE, ERIC, ProQuest theses and dissertations, Psych INFO and MEDLINE). 1437 articles were screened, with 18 reviews being identified as suitable.	63 articles within seventeen reviews examined the relationship between chronic illness and academic performance. Across all the reviews, 31 of the original articles reported the academic underperformance of chronically ill students when compared to their healthy peers. Their appeared to be a correlation between performing poorly academically and the severity of disease, diagnosis at a young age, and medication side effects. Eighty-two of the original articles found a relationship between chronic illnesses and higher levels of school absenteeism. This link was strongly associated with greater disease severity, frequent hospitalisation, non-adherence to treatment, and belonging to a minority ethnic group. Twenty original articles indicated that chronic illness could have an impact on poorer school relationships with both peers and staff, with 14 original articles also identifying difficulties with engagement in school, naming low self-confidence, and feeling different from peers as a key contributor. A higher level of understanding and support of the child's medical needs were strongly linked to a more successful reintegration into school following illness.	Not all papers reviewed were systematic. As acknowledged by Lum et al. (2017) only two of the systematic reviews met the PRISMA criteria for 'high quality' reviews. Often the original research had differing criteria for inclusion/exclusion which may impact generalisability of the results.
17	Smith, J. C., Williams, J., & Gibbin, K. P.	2003	United Kingdom (England)	Parents: N=11 School caregivers: N=11. No child participants. <u>Descriptive data</u> Childrens' medical condition: tracheotomy (N=11)	Purposeful sampling was utilised, and children were identified from the ENT department and community paediatric nursing team. Questionnaires were utilised.	All school's required training on supporting the young person. In four of the cases, there were problems with the availability of a suitable carer, and this delayed the return of children to school, in one case by eight months. This also impacted on regular attendance at school, as when carers were absent, children were unable to attend. Parents were often required to attend school to support with the needs of the child. Four families expressed dissatisfaction with their child's experiences, stating the carer of the tracheostomy, staff attitudes and funding were all contributing factors. Only half of the schools has clear emergency guidelines for supporting the young	Children's views were not sought. It is noted that some questions on the questionnaire were incomplete, but further explanation of this was not present, and it was not clear how this was mitigated in the results section. Data was considered together – it may have been helpful to consider the responses from the carers and

				Childrens' demographics: Ages: The mean age of the children was 9.7, with a range of 2-16.		person, and none of the children were on health care plans. School staff felt that up-to-date training would be beneficial. Six of the children had been excluded from engaging in school activities due to their needs.	parents separately before similarities and differences were considered. It is not clear if this sample is representative of the target population. No statistical analysis has been conducted – responses are described in prose.
18	Vanclooster, S., Bilsen, J., Peremans, L., Van Der Werff Ten Bosch, J., Laureys, G., Paquier, P., Van Bogaert, P., Willems, E., Genin, S., & Jansen, A.	2019	Belgium	Parents: N=10 Teachers N=13 No child participants. <u>Descriptive data</u> Childrens' medical conditions: Previous diagnosis of a brain tumour (N=5) Childrens' demographics: Ages: range 7-10 years old.	Part of a case study that interviewed children, parents, teachers and healthcare professionals. Semi structure interviews were conducted at the start and end of the one-year period following school reintegration. Thematic analysis was conducted.	Three main themes were identified. (1) 'the child's performance and wellbeing' (2) 'the school's attitude and approach' and (3) 'communication and working together.' Parents were consistently concerned with their child's performance, even when they were making progress. Parents were also concerned regarding their child's social wellbeing particularly around their integration back into school, and how they perceive themselves in comparison to their peers. Teachers were less concerned with the child's performance, and more focused on understanding the child's strengths and needs, as well as developing a relationship with the young person. Parents had concerns regarding school's attitude and approach and felt that their child needed to be monitored more, though development of trust in teachers alleviated this slightly. Teachers felt that they had learned specific practices to support the young person. Parents felt that they would like more contact with the school, around more than just their child's learning needs. Teachers felt that communication was more positive than parents, however they did express difficulty with regards to conflict over the needs of the young person.	Children's views were not sought. Children's academic progress was not independently measured to explore conflict between teacher and parent believes on academic progress. Teacher interviews also included counsellors who may not have been best placed to comment on academic progress. No reference is made to the relationship between researcher and participants.

19	Vanclooster, S., Bilsen, J., Peremans, L., Van Der Werff Ten Bosch, J., Laureys, G., Paquier, P., Van Bogaert, P., Willems, E., Genin, S., & Jansen, A.	2021	Belgium	Parents: N=9. Children: N=5. Teachers: N=28 Healthcare professionals: N=14. <u>Descriptive data</u> Childrens' medical conditions: previous diagnosis of brain tumour (N=5) Childrens' demographics: Ages: range 7-10 years old.	Semi-structured interviews. Qualitative content analysis was used by linking units from the transcribed interviews to the international classification of functioning disability and health childhood and youth framework (ICF).	Four key areas using the ICF were identified, (1) bodily functions, (2) activities and participation, (3) Environmental factors, and (4) personal factors. Poor mental functions were noted as having an impact on the child's functioning and wellbeing at school, as was physical recovery from treatment. Children were observed to have problems with acquiring and applying knowledge, which was a barrier to participation in school. Visual spatial tasks and motor skills were also noted to be of concern, which impacted on children participating in physical activities. Children also found reintegrating with their peers difficult. All children required either temporary or permanent adaptations to support to allow easier access to learning, with some children requiring specialist services. Teachers who had a positive attitude were associated with positive experiences. Self-esteem, the age of the young person and leisure activities all impacted on reintegration.	Researchers excluded anatomical body parts from the analysis stating that it was not relevant to the research – it may have been helpful to consider the physical impacts of the brain tumours and treatment on academic experiences. The relationship between research and participants is not explored – the researchers do not critically examine their own role. Ethics around working with children is noted, however the researchers reference using toys to elicit experiences when the children were reluctant to engage which may be argued is not considering participant wellbeing.
20	Martinez-Santos, A., Fernandez-De-La-Iglesia, J. D. C., Sheaf, G., & Coyne, I.	2021	N/A	Mixed-method systematic review of childhood cancer survivors' experiences and needs in school following treatment.	A search of six databases (CINAHL, PsychINFO, EMBASE, MEDLINE, ERIC and Web of Science) 21 studies were eligible for inclusion (13 qualitative, 6 quantitative and two mixed-method studies)	Findings were categorised under four themes. (1) Academic continuity and school re-entry, (2) physical and psychological wellbeing, (3) school life and participation, and (4) stakeholders' responses to childhood cancer. Returning to school was identified as being a difficult experience for children, and a formal plan led to an easier process of returning to education. Returning to school also provided a sense of normality for children, who cited resuming friendships as a positive – some children viewed the experience as negative, and had lower self-confidence, feeling different from their peers. Changes to physical or cognitive ability were	Differences in cancer type, age or school year were not considered. Statistical analysis was not conducted or included. Reference list harvesting/ other grey search strategies were not utilised to search for additional papers. Reference is made to reference chaining in the figures, but not under the search strategy heading.

						identified as difficult aspects for the children. Support from schools appeared to be inconsistent, with negative communication having a detrimental effect on children.	Physical and psychological wellbeing were considered together, and the review may have benefited from giving them individual consideration.
21	Hocking M. C., Paltin I., Belasco, C, & Baraket, L. P.	2018	United States of America	Parents: N=102. No child participants. <u>Descriptive data</u> Childrens' medical conditions: leukaemia/lymphoma (34%), brain tumours (24.3%) or non-central nervous system solid tumours (20.6%). Childrens' demographics: School years: 33% in pre-kindergarten – fifth grade, 53.4% in sixth – twelfth grade.	Caregivers completed a modified version of the HOPE Needs Assessment. Chi-square analysis was used to assess responses, and Cramer's V was utilised to report effect sizes.	Results were split across three categories; Problems identified, resources accessed and unmet needs. Caregivers noted a negative change in academic progress. Changes in concentration, absences and neurological conditions were given as potential reasons for the change in progress. 30% of participants noted concerns regarding the child's development, with level of concern being higher, the older the child. Caregivers noted barriers to school functioning included absences, fatigue and physical limitations. Parents noted having regular contact with school professionals, but only 25% of caregivers noted their child has been tested for learning difficulties. Older children were more likely to be receiving homebound services. 55% of respondents noted that their child was not on an education or healthcare plan. Of the parents with concerns, 63.3% had not had their child formally assessed.	Demographics of the caregivers who completed the questionnaires were not noted. Children's experiences/perceptions were not sought. School years are not consistent across countries so participants ages might have been helpful. The HOPE needs assessment contained some open questions – there is no reference as to how this data was used. Questions were often yes/no with no space for explanations that might have enriched findings. The measurements do not seem appropriate. No reference is made as to whether the sample is representative of the population. The research does not note if any participants declined to participant. The risk of nonresponse bias is not explored. It is not noted if any questions were not answered.

2.2. Overarching themes and synthesising of the data

In the service of synthesis, and through surveying the literature, the findings from the above studies were considered to have three broad commonalities: (a) communication and relationships; (b) academic performance and difficulties; and (c) the child's wellbeing.

2.2.1. Communication and relationships

2.2.1.1. Parent and Staff communication and relationships

Parents cited good relationships with staff to be a key factor in supporting the children's needs (Bruce et al., 2008). Parents preferred to have daily communication with staff (Edwards, 2018; Hopkins & Gallo, 2012; Vanclooster et al., 2019) and cited a collaborative understanding and working together as important to meeting the needs of the child (Kliebenstein & Broome, 2000; Marks et al., 2021). Parents believed that school staff should be informed as soon as possible following the diagnosis being made, or a change to condition management (Kliebenstein & Broome, 2000). Whilst there were positive examples of good communication and collaboration, distrust of school staff was a significant theme throughout the literature. Parents often believed that staff were uneducated on the needs of their child (Bowtell et al., 2018), and they had concerns regarding staff training (Smith et al., 2003), and the safety of their child as a result (Hopkins & Gallo, 2012; Edwards, 2018; Marks et al., 2021). Schools' attitude towards supporting the child significantly impacted home-school relationships, with a positive attitude fostering cohesive support for the child, and a negative attitude fostering the distrust and increased engagement of parents (Bruce et al., 2008; Vanclooster et al., 2019). Some research noted that the role of parents and the relationship with school staff was key due to the parent advocating for the child's needs in school (Dyson et al., 2011; Edwards, 2018), however parents were conscious of the stigma attached to being in regular contact with the school, and felt they were perceived negatively by school staff due to this (Marks et al., 2021). Communication between home and school was also cited as a key component for successful reintegration, and miscommunication was identified as having a detrimental impact on children when they returned to school (Martinez-Santos et al., 2021).

2.2.1.2. Staff and pupil communication and relationships

Having a positive relationship with the class teacher was a key component of chronically ill children having a good educational experience (Edwards, 2018; Vanclooster et al., 2021). Several children reported feeling that their illness had negatively impacted their relationships with their class teacher, leading to an increased difficulty in engaging in school (Dyson et al., 2007; Lum et al., 2017). Children felt that having strong relationships with an adult in the classroom was a prerequisite for achieving academically (Bruce et al., 2008), and premorbid success of this relationship often accounted for quicker adjustment following a period of illness (Irwin, 2013). Some pupils felt that staff had a lack of understanding of their needs, and that their distress was minimised (Dyson et al., 2011). Many pupils, however, felt that staff meant well, but their lack of knowledge hindered attempts to support them effectively (Bruce et al., 2008). Some children reported finding it difficult to disclose their needs in school, and either modified the information they shared with school, or shared the bare minimum needed, often due to fear of being treated differently (Kliebenstein & Broome, 2000; Freckmann et al., 2018), whilst others chose to share their condition immediately, recognising their need for support (Hoffman et al., 2019). A poor pupil-teacher relationship was also suggestive of poor psychological adjustment on a return to school, as well as poor relationships with peers (Runions et al., 2020). Some pupils also reported poor adherence to their medical treatment during school hours due to difficult relationships with staff (Dyson et al., 2011; Runions et al., 2020).

2.2.1.3. Pupil and peer communication and relationships

For children who had experienced extended time away from school, one of the main positive things cited regarding reintegration was the resumption of friendships (Martinez-Santos et al., 2021). However, this was also cited as a point of contention, with several children struggling with the realisation they were different from their peers due to their medical needs (Lum et al., 2017; Runions et al., 2020; Vanclooster et al., 2021). This difficulty managing the drive to be reunited with peers whilst accepting that their illness made them different was mitigated over time as both peers and the young person were able to adjust to the child's new needs (Vanclooster et al., 2019). Relationships between the young person and their peers was improved when efforts were made to educate the children on the young person's medical condition and their needs. Where this knowledge of the child's medical condition was lacking, individuals reported being ostracised and bullied (Bruce et al., 2008; Dyson et al., 2011; Hopkins & Gallo, 2012; Runions et al., 2020). Where the young person was able to keep in touch with their peers during prolonged absence, a sense of belonging and a positive attitude towards returning to school and being with their peers was noted (Boonen & Petry, 2012), critically however, this did not appear to be commonplace, and children reported feeling isolated during their time away from school (Lum et al., 2019b). As noted above, children did not always disclose their condition to their classmates, through fear of being ostracised (Kliebenstein & Broome, 2000; Freckmann et al., 2018), despite evidence suggesting open disclosure and development of understanding strengthened peer relationships (Dyson et al., 2007; Boonen & Petry, 2012).

2.2.1.4. Summary of communication and relationships

Across all papers reviewed, relationships and communication were consistently highlighted as a key aspect of the chronically ill children and their caregivers' experiences of education (Bruce et al., 2008; Edwards, 2018; Vanclooster et al., 2021). Parents in particular were noted to value lines of communication with the school, and where these were in place, concerns regarding staff competency and the wellbeing of the child were partially alleviated (Bruce et al., 2008). For the children, a positive relationship with a key adult had significant impact on their engagement and reintegration, though, similarly to their parents, the children felt that staff did not always grasp their needs fully (Bruce et al., 2008; Bowtell et al., 2018). Relationships with peers were positive when they were supported to understand the young person's condition and adaptations were put in place to allow for any difficulties the young person may have when carrying out activities (Bruce et al., 2008; Dyson et al., 2011; Hopkins & Gallo, 2012; Runions et al., 2020). Three of the research papers (Kliebenstein & Broome, 2000; Edwards, 2018; Runions et al., 2020) noted that these relationships might best be contextualised using Bronfenbrenner (1974)'s ecological systems theory, which will be explored further in the discussion.

2.2.2. Academic performance, engagement, and difficulties

2.2.2.1. Absence and reintegration

Absence from school was reported as having an impact on both social and academic functioning (Runions et al., 2020). Lum et al. (2019b) conducted a logistic regression on the results of questionnaires completed by 208 parents of healthy children, and 192 parents of chronically ill children, and found that that children with a chronic illness were 4.9 times more likely to have had a recent absence when compared to healthy peers (Lum et al., 2019b). Returning to school following a period of absence was an area that was noted as being difficult for children (Martinez-Santos et al., 2021), particularly as they adjusted to new limitations placed upon them due to their health (Vanclooster et al., 2019). Where a formal plan had been implemented, or where there had been continuity during a period of absence, the reintegration of the young person tended to be a positive experience (Boonen & Petry, 2012; Bowtell et al., 2018), and parents felt that the young person’s needs were met better (Kliebenstein & Broome, 2000). Smith et al. (2003) found that absences from school were often noted as directly linked to availability of care. Where children were well enough to attend, a lack of trained school staff to support medical needs was highlighted. This raises the issue of whether the absences are preventable if reasonable adjustments and support are put in place.

2.2.2.2. Academic performance and engagement

None of the reviewed papers independently measure academic performance, instead relying on self-reporting of young people and caregivers who participated in the research. Critically, this suggests that it is difficult to ascertain whether the children and their caregivers’ concerns are accurate and highlights a potential gap in the literature. Concerns around whether their child was reaching their potential and performing satisfactorily academically were cited frequently by parents (Bruce et al., 2008; Hopkins & Gallo, 2012; Hoffman et al., 2019; Vanclooster et al., 2019). Children with chronic illnesses were reported to be underperforming when compared to their peers (Freckmann et al., 2018) with gaps in attendance being cited as one reason for this impact (Runions et al., 2020). A number of articles noted that ongoing or invasive treatment for illnesses such as cancer had an impact on the young person’s cognitive functioning, which may have accounted for their academic underperformance (Vanclooster et al., 2019; Martinez-Santos et al., 2021; Vanclooster et al., 2021). Despite this admission, and the recognition that individuals may need extra support to reach their potential, only four articles referenced having extra support provided in school. Two articles stated this support was in place, (Martinez-Santos et al., 2021; Vanclooster et al., 2021) one stated support was inconsistently applied (Boonen & Pentry, 2012), and the final article noted that families felt it was needed but not given (Lum et al., 2019b). One article (Bowtell et al., 2018) noted that families chose not to disclose their child's need at all due to a lack of faith that school would provide the support needed, thus potentially highlighting further barriers for children with chronic illnesses. A number of young people and their families also felt that their academic ability was underestimated due to their medical condition (Dyson et al., 2007; Dyson et al., 2011; Vanclooster et al., 2019). One of the key consistent factors noted was that of a positive, encouraging relationship between the young person and their teacher and peers. This was felt to be a mitigating factor for academic performance by both the young person and their caregivers in a number of articles (Bruce et al., 2008; Irwin, 2013; Vanclooster et al., 2019). These articles did not highlight what the participants considered the key aspects of a positive relationship to be. Hocking et al. (2018) noted that children were often not in receipt of academic support such as Individual Education Plans (IEPs). The response option to this question for parents was yes or no, with no space for parents to note children may be undergoing assessment for the plan, or to give a reason for why their child was not on a plan.

2.2.2.3 Staff Knowledge

Staff's understanding of the needs of the young person and their medical condition had a significant impact on engagement and support in school, as well as developing trust and rapport with parents and the young person themselves (Runions et al., 2020). For parents, a significant concern was staff understanding of the needs of their child, with several citing that they were concerned staff did not understand the severity of their child's illness, and the adaptations needed to support the young person (Bowtell et al., 2018; Marks et al., 2021). For parents, this lack of understanding often correlated with a lack of adaptation in class (Hoffman et al., 2019). Parental concerns were not unfounded, with children and young people reporting that they were denied access to medical treatment, or felt they were being discriminated against due to staff's lack of understanding (Dyson et al., 2011). It is of note that the children who stated that they were denied access to medical treatment and basic needs such as water or the toilet were children who had the medical condition sickle cell, a condition that is usually found in individuals who are from a black ethnic group (Dyson et al., 2007). Further research is needed, but it raises the question of possible broader systemic racism in the education system (Gillborn, 2018), which may further disadvantage children with chronic illnesses.

2.2.2.4. Summary of Academic performance, engagement, and difficulties

Absence from school was noted as being one of the major barriers to academic performance and engagement (Runions et al., 2020) with chronically ill children being more likely to have an illness-based absence than their healthy peers (Lum et al., 2019b). Formal plans of reintegration are noted as being key to successful returns to school, and therefore academic engagement (Boonen & Petry, 2012; Bowtell et al., 2018), though these did not appear to be routinely put in place for children. Parents often cited concerns regarding their child's academic progress (Bruce et al., 2008; Hoffman et al., 2019) and reported that their child was underperforming when compared to their healthy peers (Freckmann et al., 2018). However, no independent measure of the child's academic performance was conducted, and all but one study lacked a comparative control group. Children and their caregivers often felt that their academic ability was underestimated by staff in school (Dyson et al., 2007; Dyson et al., 2011; Vanclooster et al., 2019). Settling back into learning was noted to be difficult, though positive relationships with staff in school went some way towards mitigating this (Bruce et al., 2008; Irwin, 2013; Vanclooster et al., 2019). Lack of understanding from staff, and a lack of adaptations in the classroom were both noted as being a hindrance to academic progress (Bowtell et al., 2018; Marks et al., 2021). Children noted that this lack of understanding on occasion led to them being denied medical treatment (Dyson et al., 2011).

2.2.3. The child's wellbeing

2.2.3.1 Emotional and Social needs

Of note are concerns regarding the children's emotional and social needs. Where children were absent from school for a significant period, caregivers believed being able to receive some form of homebound tuition was beneficial to the children, stimulating their development, and promoting good emotional wellbeing (Boonen & Petry, 2012). This, however, was not the norm in the research evaluated, and critically highlights that chronically children may be ‘forgotten about’ when they are not in school (Lum et al., 2019a). Whilst the return to school was highlighted as positive for the children in terms of a return to normal, it was also a difficult experience for the children and young people (Vanclooster et al., 2019) due to need to re-establish friendship groups and understanding (Bruce et al., 2008), or due to difficulty with academic demands (Vanclooster et al., 2021). These difficult experiences were alleviated by a robust transition plan back into the education setting (Martinez-Santos et al., 2021) though only two articles in the systematic review felt school had considered this (Tresman et al., 2016; Vanclooster et al., 2019). Parents reported concern with their child’s emotional wellbeing, with Lum et al. (2019b) reporting that following logistic regression analysis, parents of chronically ill children were likely to report high emotional distress 2.2 times more often than parents of healthy children. Similarly, parents of chronically ill children were 4.6 times more likely than the control group to report their child had low confidence (Lum et al., 2019b). Critically, it might be noted that this research considered parental reports, where anxieties around their child’s wellbeing may already be heightened (Dawson, 2018). Similar findings were reported by Lum et al. (2017) and Vanclooster et al. (2021), with Runions et al. (2020) reporting that acceptance by peers was a significant factor impacting on a young person’s ability to thrive socially and academically. This was echoed by Freckmann et al. (2018) who reported that children stated they had often had difficulty engaging due to their anxieties regarding their medical condition.

2.2.3.2 Physical and medical needs

A further concern noted in these studies was the lack of support for children when managing their medical condition. Children noted that they felt fearful about asking to be let out of the classroom to tend to their needs, and often chose to avoid seeking medical attention, or taking routine medication rather than face discipline for leaving the classroom (Dyson et al., 2011). It might be argued that this has not only a detrimental effect on the physical wellbeing of the young people, but also impacts on their emotional wellbeing, as well as their academic engagement (Freckmann et al, 2018). If a child is worried, or physically unwell, it would be expected that this would have a detrimental effect on their learning (Runions et al., 2020). Furthermore, children often found accepting new physical limitations difficult, as it highlighted the gap between themselves and their peers further (Vanclooster et al., 2019). It might be suggested that these physical limitations can be mitigated by teachers who are willing to work collaboratively with the child to find innovative strategies for the young person to overcome their newfound limitations (Bowtell et al., 2018). Crucially, little research has considered the physical or medical needs of children with chronic illnesses when attending school (Dyson et al., 2011; Vanclooster et al., 2019), instead tending to focus on emotional or social needs (Bruce et al., 2008; Lum et al., 2019a), thus highlighting an area for future research.

2.2.3.2 Summary of the child's wellbeing

Return to school following a period of illness was noted to be a critical aspect of children's social and emotional wellbeing. Whilst reuniting with peers was a positive, realising their newfound limitations was a low point for children with chronic illnesses (Vanclooster et al., 2019). Acceptance from peers was noted to be a protective factor for children who have chronic illnesses (Runions et al., 2020), though Lum et al. (2019b) noted that chronically ill children were still significantly more likely than their healthy peers to be reported as experiencing emotional distress and low confidence by their parents. Children were also noted to have heightened concerns around potential punishments for needing to take medication or leave the classroom, and as such noted poor medical adherence (Dyson et al., 2011).

Section three: Discussion of findings and summary

1.1. Discussion

The aim of this discussion is to synthesise and summarise the literature across both section one and section two of the review.

The number of people who are being diagnosed with chronic health conditions is increasing regularly and is expected to affect over half of the population by 2025 (The World Health Organisation, 2022; The European Respiratory Society, 2022). When a child has a chronic illness, it is evident from the literature that the impact is far reaching, and can influence the young person (Lum et al., 2019b), their family (Havill et al., 2019), and the professionals who work with them (Duggan et al., 2004). It could be suggested that the impact of chronic illnesses is vastly underestimated, with a lack of consideration given to the long-term physical and emotional impacts of having a chronic illness (Lum et al., 2019b), with children experiencing difficulties for up to three years after reintegrating into an education setting (Prevatt et al., 2000).

The current literature suggests that for a child with a chronic illness, education can be a difficult experience, with their illness impacting on their educational progress, emotional wellbeing, and friendships (Lum et al., 2019b). Most of the research so far has looked at the experience of chronically ill children from the parents' perspective, with limited research including the views of the young people themselves.

For parents of chronically ill children, managing the needs of a family, looking after their own wellbeing, and remaining in employment whilst advocating for their ill child can often be an overwhelming responsibility. Edwards (2018) noted that it might be helpful to consider the impact on the family system through the lens of Bowen (1993) family system theory, which considers families to be a unit, and therefore suggests that an emotional reaction from one member, will be present in the others. Critically, this theory focuses largely on adults in the family, and the impact their emotions may have on other members (Brown, 1999), with little consideration as to how the children may impact the family.

When considering their relationship with school, parents report feeling as though school staff perceive them negatively, and that they are often viewed as having a lack of knowledge regarding the education system (Marks et al., 2021). Caregivers reported feeling that frequent communication with school staff is beneficial, due to this supporting a collaborative approach of meeting the child's needs (Edwards, 2018). Where a lack of collaborative working and open communication was noted, parents harboured increased distrust of the school, and were more likely to note that they felt school staff were uneducated in the needs of the child and lacked adequate training to properly care for the young person when they attended school (Marks et al., 2021). Often, parents cited concerns about whether their child was safe when in an education setting (Hopkins & Gallo, 2012). These fears were not unfounded, with Smith et al. (2003) finding that parents were required to attend school on a regular basis to help meet the medical needs of their child, and Dyson et al. (2011) noting children were denied access to medical treatment.

Parents of chronically ill children also cited academic progress to be of significant concern (Bruce et al., 2008; Hopkins & Gallo, 2012; Hoffman et al., 2019; Vanclooster et al., 2019). Many parents felt that their children were not meeting their potential academically, and that appropriate adaptations were not in place (Boonen & Petry, 2012; Lum et al., 2019b; Martinez-Santos et al., 2021; Vanclooster et al., 2021). For some parents, there was such a significant lack of trust that the school would make adaptations, that often, they would choose not to disclose medical conditions due to believing it would not make a difference (Bowtell et al., 2018). Whilst a lack of adaptations was stated as one issue with the child making progress, other potential barriers included the level of absence when compared to their healthy peers that a child with a chronic illness experienced, as well as the impact that being unwell, or invasive medical treatments can have on the young person (Vanclooster et al., 2019; Martinez-Santos et al., 2021; Vanclooster et al., 2021) , possibly leading school staff to misunderstand the child's performance as their potential. A further concern of parents was the reintegration of pupils back into the classroom setting, following a period away due to illness. Many parents felt that when this reintegration was planned for, their children had a positive experience of returning to school and adapted to learning far quicker than those who did not, even when school staff felt anxious, or unprepared for the return of the child (Boonen & Petry., 2011). This suggests that parents accept that while school staff are not always equipped for supporting children with chronic illness, a willingness to learn and try to meet children's needs provided a far better foundation for the experiences of all involved (Edwards, 2018).

Where the research did include the voice of the young people themselves, their priorities were markedly different to that of their caregivers. The children’s biggest concerns were around their friendships, and the social interactions they have with their peers (Bruce et al., 2008). For children, returning to school was a markedly positive landmark in the journey of having a chronic illness, as it meant they were reunited with their friends. It was however, often marred by the fact that the children were often unable to keep up with their peers as they had been able to previously, both in a physical sense on the playground, and in an academic sense, in the classroom (Vanclooster et al., 2019). For children where there was a strong relationship with their class teacher and their peers, these difficulties were soon overcome (Boonen & Petry, 2012). For those who had poorer relationships, the gaps widened. Of note, the biggest impact for a young person with a chronic illness was their relationship with their class teacher, as this appears to be the catalyst for all other aspects of their school life falling into place (Vanclooster et al., 2021). If the chronically ill child has formed a positive bond with their teacher, they are more likely to foster positive relationships with their peers, perform well academically and adhere to their medical treatment in school (Runions et al., 2020). Where children reported poorer relationships with staff, they were often less likely to disclose medical conditions, or periods where they felt unwell, more likely to have poor peer relationships and report feeling ostracised, and more likely to have poor medical adherence when in the care of school staff (Dyson et al., 2011).

Though little reference is made to theory overall, three of the research articles (Kliebenstein & Broome, 2000; Edwards 2018; Runions et al., 2020) noted the importance of Bronfenbrenner (1977) ecological systems theory. Bronfenbrenner's (1977) model is generally well regarded, with Hayes et al. (2017) noting that it is a holistic approach to considering the lived experiences of children and young people. There is a paucity of research on the interaction between the mesosystem and the child (Leventhal & Brooks-Gunn, 2000), and it is difficult to establish whether the systems are a direct cause of any effects noted. Lippard et al. (2018) investigated Bronfenbrenner's theory through examining teacher-pupil relationships, finding that academic attainment and classroom behaviour are significantly influenced by this relationship. Similarly, a positive inclusive school ethos (Wilson et al., 2002) and a whole school approach to health (Langford et al., 2014) can have a significant impact on pupil relationships, wellbeing, and academic achievement. These findings echo those noted above, highlighting the importance of positive pupil-teacher relationships (Vanclooster et al., 2019).

It is additionally important to consider the current climate for children with chronic illnesses. The Coronavirus pandemic has changed the educational landscape for all children, and its impact, particularly on those with a chronic illness, cannot go unacknowledged (Welsh Government, 2020). Whilst research into the impact of the pandemic on chronically ill children is ongoing, early research is suggesting there has been a mixed experience (Serlachius et al., 2020). Whilst the Pandemic has likely increased health anxiety for these children, and confounded their educational experiences further, the introduction of public health mitigations is also likely to have meant children with chronic illnesses have had better school attendance due to reduction in illness (Olsen et al., 2021).

1.2. Limitations and critiques

There are several limitations in regard to this major literature review. It is of note that several authors had more than one study included in this research, which may in turn lead to their subjectivity on the needs of children and young people with chronic illnesses being overrepresented. Similarly, much of the research did not adequately consider the researcher-participant relationship, with a lack of critical consideration regarding the researcher's own role, potential bias, and influence (Singh, 2013). The research reported on relied heavily on self-reporting of the impact of being chronically ill on the children and their educational experiences. There were no studies that included actual assessment of the children's academic ability to prove/disprove the views of those interviewed, nor independent verification of absence from school. It is of note that the reviewed papers primarily focused on children with severe disease who have missed significant amounts of their education thus far. Should the research have included children with well controlled conditions, it is possible that the results may have given a different picture of the experiences children and families have experienced. Some studies analysed secondary data which may have led to misinterpretation of the data. Data provided is mostly from mothers, and on occasion the young person themselves. The research is also from Western countries with comparative educational and healthcare systems. These findings may not be representative of children living in countries other than those in the Western world.

1.3. Summary & Rationale for current study

Children who are chronically ill are a unique subsection of the school age population. Often, they are academically able (Hilliard et al., 2015), however ongoing medical needs can lead to large gaps in education, where the child is unable to attend school. Moreover, it can be considered that for parents, there is a significant level of concern regarding the child’s wellbeing, and progress in school, as well as how staff will approach treatment plans (Smith et al., 2003). This research hopes that further understanding of the experiences of both the young person and their caregiver will lead to greater understanding, and thus improve school experiences, reducing the negative impact on families where there is a child with a chronic illness.

This literature review evidences that the experiences of education for chronically ill children and their caregivers are often complicated. Caregivers are key individuals who can give insight into the experiences of advocating for a child with a chronic illness. Naturally, it is also important to consider the experiences and views of the child themselves. The role of the educational psychologist in Wales views person centred approaches, and therefore the voice of the child as central to good practice (ALNET, 2018). Additionally, caregiver input is seen as key to promoting change, due to the expert role and experiences that caregivers have (De Geeter et al., 2002).

Whilst the search term ‘chronically ill children’ yields a large number of results, the focus has tended to be on the experience of being chronically ill as a whole, or the impact of medical intervention on the child. There has been relatively little research that looks at either parental or child experiences of education when the child is chronically ill, and a smaller subsection again that considers the views of both parties. Critically, the literature considered in this review has typically focused on parental and child experiences of education in a secondary nature – e.g. interviews were focused on exploring the young person's experiences of being chronically ill in general, and a subordinate theme that emerged was regarding education (Hopkins & Gallow, 2012). Children's experiences were not always sought, and when they were, it was through the use of questionnaires where further exploration of answers was not possible (Boon & Petry, 2011), or where generalisability of experiences was difficult due to a wide range of experiences (Bruce et al., 2008; Dyson et al., 2011; Vanclooster et al., 2019). Several of the papers focused on specific conditions, rather than including a wide range of needs (Dyson et al., 2007; Dyson et al., 2011; Vanclooster et al., 2019). This highlights the gap in research focused solely on families with a chronically ill child's experiences of education. Similarly, no identified research considered the needs of children and young people with chronic illnesses through the lens of an educational psychologist, further highlighting the rationale for this study. The present research hopes to fill this gap through exploring the experiences of both children and their caregivers in detail.

1.4. Research aims

This research aims to answer two questions;

- What are chronically ill children's experiences of education? And
- What are the caregivers of chronically ill children's experiences of education?

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The experiences of families of Children and Young People with chronic illness within education

Part Two: Empirical Research Paper

Word count: 9278

1. Introduction

Children with chronic illnesses are a small but highly vulnerable group in UK schools (Lum et al., 2019). Debate is ongoing as to how chronic illness is defined, however there is general agreement on the definition needing to include reference to an ongoing condition that will require regular follow up from specialist services (Wijlaars et al., 2016). In England, 14.1% of the population had been diagnosed with a long-term illness, disability, or medical condition by the time they reached the age of 15 (Public health England, 2015). In Wales (Public Health Wales Observatory, 2011), the last reported data found that 5.7% of males and 4.3% of females aged 0-24 identified as having a long-term illness, disability, or medical condition. Due to the varying definitions used to identify a chronic health condition, it is difficult to know how accurate this data is, with Miller et al., (2016). suggesting prevalence may be as high as 31%.

Having a chronic health condition has a significant impact on not just the young person's social, emotional, physical, and academic development (Lum et al., 2019), but also on their family (Havill et al., 2019) and others around them (Papadatou et al., 2002). Despite this, there is often limited support available to chronically ill children to help them when they are attending an education setting if they do not also have significant learning needs (Irwin & Elam, 2011). Children with chronic health conditions have higher absence rates than their healthy peers (Lum et al., 2019) which leads to them missing significant academic input (Runions et al., 2020) and performing poorly when compared to healthy peers (Freckmann et al., 2018). Even when chronically ill children have the potential to reach the same academic levels as their peers, they are consistently underestimated by those around them (Dyson et al., 2007; Dyson et al., 2011; Vanclooster et al., 2019).

Children with chronic illness can often experience difficulty with social skills and developing and maintaining friendships (Carter et al., 2015). Parents reported that chronically ill children were significantly more likely to have low self-confidence, and high emotional distress (Lum et al., 2019; Vanclooster et al., 2021), as well as an increased risk of developing psychiatric disorders as they age (LeBlanc et al., 2003). Robust, ongoing social connections with peers were identified as being key mitigating factors for children when reintegrating into school and were a significant factor in social and academic achievement for chronically ill children (Runions et al., 2020).

Parents’ confidence in staff knowledge and ability can impact on how a chronically ill child experiences school. Parents often believe that school staff do not understand the severity of the child’s medical conditions (Hopkins & Gallo, 2012), nor do they have adequate knowledge on the adaptations needed to support the children when they are attending school (Bowtell et al., 2018; Marks et al., 2021). Parents and children both report a lack of adaptations (Hoffman et al., 2019), discrimination (Freckmann et al., 2018) and lack of access to medical treatment (Dyson et al., 2011). This distrust between parents and school staff can lead to negative school experiences for children with chronic illnesses, as collaborative working between home and school is cited as a key component in good educational experiences for children and young people (Kliebenstein & Broome, 2000; Marks et al., 2021). Parents were significantly more likely to have increased engagement with the school when they felt staff did not have a grasp of their child’s needs, leading to a perception that they were negatively viewed by school staff (Bruce et al., 2008; Vanclooster et al., 2019). For children who are chronically ill, positive relationships with staff are a key indicator for engagement in school, as well as academic learning (Dyson et al., 2007; Bruce et al., 2008; Lum et al., 2017). A good relationship with staff was also noted to be a prerequisite for a positive peer relationship (Runions et al., 2020). Poor relationships with staff can also lead to children not adhering to medical treatment, due to the need to request to leave class or ask for support with accessing medication (Dyson et al., 2011).

Educational psychologists (EPs) work with children, their families and school staff to help identify children’s strengths, build their resilience and wellbeing, and help increase their learning and academic achievement (Welsh Government, 2016). They are therefore in a strong position to advocate for the needs of children with chronic health conditions. With the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 (ALNET, Welsh Government, 2018) an increased focus is being placed on collaboration between education and health when working to meet the needs of children and young people. EPs will need to ensure they have a strong understanding of the barriers that children and their caregivers face when attending an education setting when chronically ill in order to advocate for these families.

1.1. The current study

There is a wealth of research that explores the experiences of children with chronic illness (Aparecida Vieira & Aparecida Garcia de Lima, 2002; Carter et al., 2017). There is also significant research that examines the lived experiences of family members (Andersson-Segesten & Plos, 1989; Case-Smith, 2004; Gan et al., 2018), and that of professionals working with children who are chronically ill (Mescon & Honig, 1995; Meuleners et al., 2002; Berger et al., 2018). There is little UK based research, and limited research that looks at the perceptions of education from both parent and child (Bruce et al., 2008). There is a lack of current research that considers the views of the caregivers and the young person themselves in the context of education. This research hopes to (a) explore the educational experiences of children with a chronic illness, and (b) the experiences of parenting a child with a chronic illness, with a specific focus on the experiences of navigating the education system.

1.2. The research questions

This study explored two research questions:

1. What are the chronically ill childrens' experiences of education?
2. What are the caregivers of chronically ill children's experiences of the education system?

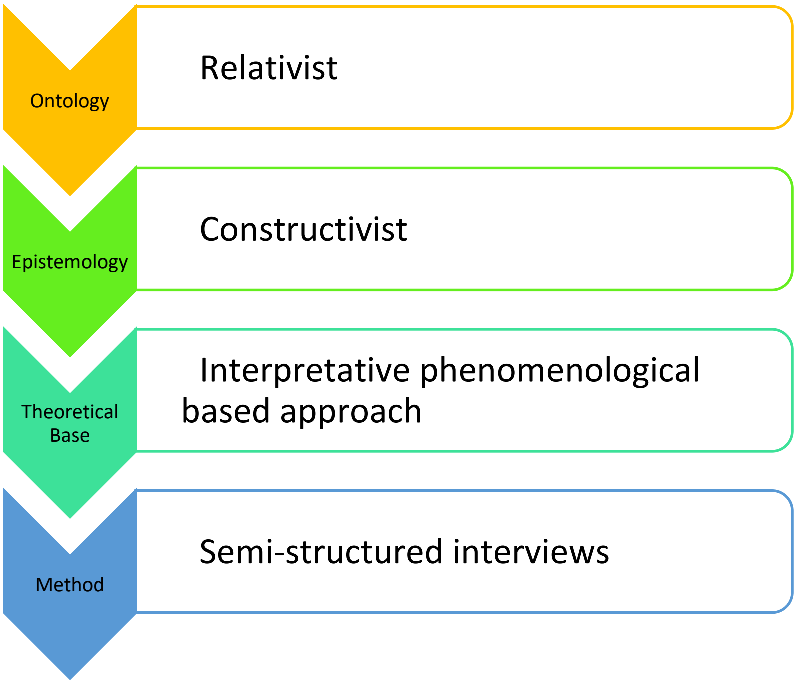
2. Methodology

2.1. Theoretical Framework

The theoretical framework which informed this research is shown in figure 2.

Figure 2

Theoretical framework informing this research



2.2. Ontology and epistemology

The researcher’s philosophical belief and research position informs the type of research that will be undertaken. Ontology is understood to be how individuals understand and perceive reality, namely the beliefs that they have of the world, whereas epistemology concerns itself with how knowledge is acquired (Guba & Lincoln, 1994).

This research takes an ontological stance of relativism, and an epistemological stance of constructivism. A relativist ontological position has been chosen as it reflects an individual’s experiences and their understanding of these experiences can be researched (Moon & Blackman, 2014). This research examines the individual realities of children with chronic illnesses, as well as those who care for them.

The constructivism epistemological stance reflects the researcher's philosophical belief that knowledge is subjective, that each individual in this research will have their own interpretations of their lived realities, and that the participants actively work to make sense of their reality (Smith et al., 2009; Braun & Clarke, 2013).

2.3. Methodological approach

This study chose to use interpretative phenomenological analysis (IPA) as an approach, as the principles of IPA fit with the fundamental stance of the ontological and epistemological positions (Smith et al., 2009). IPA is used as an approach to research, rather than a method for analysis, as it underpins all aspects of the research design (Smith et al., 2009). IPA allows participants to share in depth accounts of their experience of a phenomenon, in this case, experiences of education and chronic illness, and what this has meant to them. (Smith & Shinebourne, 2012). IPA is an ideographic approach, meaning it explores the experiences of a fairly homogenous group who have all experienced a similar phenomenon (Smith et al., 2009). In the case of this research, IPA was considered an appropriate approach for exploring the experiences of two separate groups; caregivers and their children when navigating the education system with a chronic illness, what these experiences meant to participants, and how they made sense of them.

IPA was chosen over other possible methods due to the fact it goes beyond the surface, allowing the researcher to get alongside the participant and begin to draw meaning from the experiences, building a deep understanding of what these experiences mean to the participant, and how it has impacted their lives (Smith & Shinebourne, 2012).

2.4. Procedure

The research procedure can be seen in figure 3.

Figure 3

Research procedure and recruitment process

Gatekeeper consent

Ethical approval was granted in June 2021. A gatekeeper letter was sent to seven charities, and two social media groups (see appendix B). One charity declined to circulate the information, one agreed to circulate via social media and five did not reply. One social media group also agreed to advertisement.

Advertisement of Study

Information about the study went live online in July 2021. The researcher created a recruitment poster (appendix C) which was circulated via social media.

Contact with participants

One participant got in touch via a social media group, the other emailed to express their interest. Both caregivers were sent the participant information sheets for both themselves (appendix D) and their children (appendix E). Once they confirmed they were happy with the premise of the study, consent forms were signed (appendix F & G) and interviews were arranged.

Interviews

Four interviews were conducted in July 2021, the remaining two in October 2021. Before beginning the interview, the researcher reviewed the information sheet and consent form with participants and confirmed there were no further questions. The semi-structured interviews (appendix H) took place via Zoom and followed a prepared interview schedule. The interviews lasted between 37 & 82 minutes. Each participant was debriefed following the interview and emailed debrief forms (appendix I & J) following the interview sessions.

2.5. Sampling

Due to the idiographic nature of IPA (Smith & Shinebourne, 2012), a purposeful approach to sampling was taken (Suri, 2011) Though this meant that the data could not be generalised, it allowed for a fairly homogeneous sample to participate (Smith et al., 2009). Smith et al., (2009) suggests a sample size of 4-10 interviews for doctoral research, which aligns with the number of interviews completed in this study (N=6). The researcher sought to recruit family units. Two family units participated. One parent participant had two children participating in the study and therefore conducted two interviews, one for each of their children. See table 3 for participant inclusion/exclusion criteria.

Table 3

Inclusion and exclusion criteria for participants

Inclusion Criteria	Exclusion Criteria	Inclusion/exclusion criteria rationale
● The child had a medical condition that met the definition of a chronic illness as defined by Wijlaars et al. (2016, p882) *'Any health problem requiring clinical follow-up for >12 months... Medical follow-up was defined as repeated hospital admission, specialist follow-up through outpatient department visits or use of support services such as physiotherapy or speech and language therapy.'* ● The child was aged 11-16 and in education ● The child had an attendance that was 90% or below what would be expected for a pupil attending school full time. ● The children were required to give consent for the family units to	● The child was below the age of 11, or 17 or over ● The child's medical condition was expected to last less than 12 months, or did not require follow up appointments with a medical professional ● The child had additional learning needs (E.G. Dyslexia, ADHD, ASD)	● The age criteria was chosen to allow for a fairly homogeneous group of children who were experiencing a similar area of education. ● Medical condition criteria recognised an agreed definition for a chronic illness and excluded individuals who may have a temporary condition (e.g., a broken leg that required adaptations and physio, but is unlikely to be a chronic condition). ● Government guidance (Department for Education, 2019) for 'persistent absence' was used to help create a fairly homogenous group of participants. ● Children with additional learning needs were excluded in an attempt to hone in on the phenomena, and to attempt to reduce the likelihood of other confounding factors.

participate in the research.		

2.6. Recruitment

The recruitment process is detailed in figure 3. Five participants were recruited from two families, and their demographics are noted in table 4. Names have been altered, and medical conditions excluded to allow for anonymity. An anonymised description of the conditions has been included to support ease of reading.

Please see section 3.3.2 in paper three for reflections on the recruitment process and learning gleaned from this.

Table 4

Participant demographics

#	**Pseudonym**	**Location**	**Parent/Child**	**School year***	**Anonymised information on conditions**
1	Sarah	England	Parent of Emily and Joe**	N/A***	N/A***
2	Emily	England	Young Person	Year 6 into year 7	Neurological condition & a blood disorder
3	Joe	England	Young Person	Year 7 into year 8	Condition that causes immune system deficiency & a genetic disorder
4	Sophie & Ian	England	Parents of Morgan	N/A***	N/A***
5	Morgan	England	Young Person	Year 12/first year of college	Neurological condition

** Some of the interviews were conducted in the summer holidays, so the children were between school years*
***Sarah conducted two separate interviews, one for Emily and one for Joe*
**** These are N/A due to being the parental participants and therefore not having a school year/medical condition*

2.7. Conducting the interviews

The researcher met with participants through the online platform Zoom. The interviews generally began by asking about the child's medical condition, when they were diagnosed and what that meant to them or their caregiver, before moving on to talk about what school was like. The researcher had a list of questions (see Appendix H) but often followed the lead of participants whilst talking about their experiences. The children were offered ice breakers and end of interview games, though none chose to take these up. The audio was recorded using the Zoom application and stored on an encrypted device. The researcher transcribed each interview then deleted the audio recordings (see Appendix P and Q for example transcripts with annotation, or the separate document for full original transcripts). Children were offered the choice of interviewing alone (n=1), or with their caregiver present (n=2).

2.8. Data analysis

IPA in its nature does not have a set approach to data analysis. However, Smith et al. (2009) recognised that for the novice researcher, guidance to analysis would be beneficial. As such the researcher used the suggested approach to data analysis as demonstrated in Appendix K.

2.9. Ethical considerations

The Cardiff University School of Psychology Ethics Committee granted full ethical approval for this research study in June 2021. Further information on ethical considerations can be seen in appendix L.

2.10. Validity/Trustworthiness

Validity is naturally difficult to evidence when using a method such as IPA, however, it is important that the data is trustworthy. Yardley's (2008) criteria for assessing qualitative research was used to help evidence this. See appendix O for further detail.

2.11. Researcher Position

The use of IPA can create a level of tension for the researcher (Noon, 2018). They must balance possible preconceptions of the topic to avoid leading or biasing the interview questions, whilst recognising that prior knowledge can also be beneficial as it allows the researcher to have insight into the topic (Finlay, 2008). Similarly, in the course of the interview the researcher must balance not influencing the participant yet being involved enough to promote discussion (Smith et al., 2009).

Moreover, IPA naturally invokes a double hermeneutic, as the researcher is interpreting the participants' own interpretations of their experiences (Smith et al., 2009; Smith & Shinebourne, 2012). In this study, a triple hermeneutic was present, as parents would naturally fall into talking about how they believed their child had felt, when describing incidents that had taken place. The researcher position and management of these issues is explored in part three.

3. Findings

This section presents the findings from the data analysis of both parental and child interviews. The subordinate themes for both groups of participants were initially developed from each transcript through multiple readings of each transcript. They were then categorised and grouped into the resulting superordinate themes. Key quotes from participants are utilised here to provide meaning and context to the interpretations. The full list of quotes for each theme can be seen in appendix M for parents, and appendix N for children. Analysis was split into parental and children's experiences to reflect their experiences of the phenomena from different perspectives, and to keep the analysis fairly heterogeneous.

3.1 Parental experiences

The superordinate and subordinate themes for parents can be seen in table 5. The table also indicates whether the theme was present for each interview.

Table 5

Superordinate and subordinate themes for parent participants

Subordinate themes	Sarah (Joe's Interview)	Sarah (Emily's interview)	Sophie & Ian
Superordinate theme 1: the importance of relationships			
Relationship with staff	Yes	Yes	Yes
Staff knowledge & perceptions	Yes	Yes	Yes
Being an advocate	Yes	Yes	Yes
Superordinate theme 2: The perceived impact on the family			
Where do they belong?	Yes	Yes	Yes
Friendships	Yes	Yes	Yes
Managing my own emotions	Yes	Yes	Yes
Superordinate theme 3: School isn't for chronically ill children			
Systemic issues/ the battles	Yes	Yes	Yes
Being left out /punishments	Yes	Yes	Yes
Home learning	No	Yes	Yes

3.2. Superordinate theme 1: The importance of relationships

This superordinate theme examines the relationships between parents and school. It considers how parents believed their relationships with staff members, as well as staff knowledge and attitudes regarding the child’s chronic condition impacted on the experiences of the family. It also highlights the conflict parents can feel in their role as an advocate.

3.2.1. Relationships with staff

Parents talked to two different experiences when thinking about relationships with school staff, the positive experiences, whereby the outcome was a happy school environment, conducive with good learning and outcomes for the young person, and conversely an environment where there was tension between parents and school staff, and therefore a negative impact on the young person. Sarah in particular had experienced both sides of the coin. When talking about the positive relationship she had with a member of staff, she reflected on how this meant that Joe had the best learning environment possible, as she was able to work collaboratively with the school to help them understand his medical needs. She also suggested she finds comfort in the relationship, indicating that consistency and collaboration meant they truly understand Joe and his presentation.

‘Um, and it's given me some consistency because it's that same person contacted me each time… But um, yeah, the communication, that side of it's been better.’ Sarah (Joe’s interview) line 372-376.

This is at odds with her usual experiences with school, and previous negative relationships have led to Sarah making the decision to move the children to new schools. She suggested that schools will only offer help if they like parents, and therefore as a mother she is carrying the burden of whether schools will provide the necessary support to meet the needs of her children. Sarah alludes to the fact that there is a balance to be struck in advocating for her children – advocate too little and the children may not get the help they need, advocate too much and staff will perceive her to be an overbearing parent and judge the children’s needs to not be as great.

‘I'm really consciously aware of how I talk to schools and what I say, and I’m really worried about how I come across. It's, uh, it makes it very difficult to ask for help, because you don't want to come across... Get them, Get on the wrong side of them because once the school, get an idea in their head of who you are, getting help becomes insanely difficult.’ Sarah (Emily’s interview) lines 587-592

This indicates that Sarah believes positive relationships with school staff are the crux of getting support. She indicated that having open and honest lines of communication with a key member of school staff allow her to focus on the children’s needs, rather than carefully curating her image during meetings and subsequently worrying about how she is being perceived, and whether she meets the criteria of receiving support for her children.

3.2.2 Staff knowledge and perceptions

Similarly, staff knowledge with regards to medical conditions was also perceived to have a significant impact. Staff being willing to learn, and an openness to listen to parental explanations had a positive impact of parental trust in the school. Sophie and Ian explained how staff knowledge of Morgan’s condition was a hugely important part of their positive experience.

Um, before he was head of year, he was like his form tutor for year seven and year eight. His best friend from university has [condition]. [okay] And so he understood. Umm, and he was the biggest advocate for [child] really, wasn't he? [yeah] to the point that if needed- you know there were times we couldn't get through to [child] to say you need to set this back, and he would say to him '[child] you know the time has come that you can't do this, you can't, can’t go in' Sophie and Ian, line 225-229.

There is a suggestion here that school were able to take on the role of the ‘bad guy’ due to their understanding of Morgan’s needs, allowing them to recognise when he needed to rest. There is also a sense that Sophie and Ian did not need to constantly be fighting Morgan’s corner, as they had somebody at school willing to take on the role of ‘advocate.’ Morgan’s parents allude to the fact that they receive significant pushback from Morgan when they attempt to provide boundaries, whereas Morgan appears to respect and listen to school staff when they do the same, this may be due to how Morgan constructs the role of his parents, vs the role of school staff.

Sarah speaks of how there is a disconnect from the school staff she has interacted with. On one hand, some staff present as fearful, whereas others are almost dismissive of need. There is a suggestion that Sarah wants a middle ground for her children, where she is listened to, but the children are also given the chance to try different activities safely. Sarah's confidence in letting this school push Joe appears to stem from the fact they are more collaborative with her, indicating that a good relationship leads to better staff knowledge and a positive environment for the children.

'They've been less afraid, to push him and see what he can do.' Sarah (Joe's interview) line 389.

Whilst Sarah is now experiencing positive interactions with school staff and their knowledge, this has not always been the case. She reflected on the frustration she felt when staff heard Joe had received an additional diagnosis, and they automatically assumed he would be treated like other children with the condition, rather than viewing Joe as an individual child with individual needs. Sarah reflects on how she believes school staff perceive all children with medical conditions to be the same – this may fuel Sarah's distrust as to whether school staff will meet Joe's needs as if school are dismissive of his individual circumstances, how can Sarah trust them to follow the medical processes to keep him safe. This might further highlight how she feels the need to continuously communicate with school to ensure medical processes are being followed.

'We started to have a few issues, like, that was when he got diagnosed with the [condition]… the problem was, They'd had children in before who'd had [condition], and they just assumed [child] would be like them, you know, they're like, 'oh we know about [condition].' And when we went in to do the training they're like, 'Yeah, we know we've done this before.' Sarah (Joe's interview) Line 117-121.

Staff willingness to learn about the medical condition of the child, and open, collaborative communication with parents seem to be the foundations for building safe trusting environments for the young people to thrive.

3.2.3. Being an advocate

Sarah in particular, talking about having to advocate, or fight for her children. There was a frustration that school were not working with her on meeting the needs of the children. There is an underlying sense of Sarah needing to keep pushing the school for change, as they are not placing the same value on her children's needs. Sarah's frustration that school staff have not prioritised a medical handover with new school staff is clear. She stumbles over her words as she reflects on how, once again, her child's safety is school has fallen to her to address.

'*Everything's been left to me to manage… So if I hadn't chased it, they wouldn't even have known he had medical stuff before he... so I, I chase all that.'* Sarah (Joe's interview), lines 348-352.

There is a sense of 'out of sight out of mind' and the fight for keeping her children present in the minds of those who teach them.

'So it was, you'd lose complete track of what was going on in school unless I asked my mum friends and found out from them what they were doing.' Sarah (Emily's interview), lines 145-147.

3.3 Superordinate theme 2: The perceived impact on the families

Throughout the interviews, the parents spoke of the experiences their children had, and how they felt managing their children's needs and emotions. Similarly, the parental participants also reflected on the toll that the experiences have taken on them as caregivers. This theme acknowledges the perceived impact these experiences had on the child and their caregivers, and how this influences parental approaches.

3.3.1 Where do they belong?

A sense of belonging was seen as a key aspect for parents, and a foundation from which children could begin to join in and build friendships. As all the children aged, there was an acute awareness that they were different from their peers, and parents often felt the need to take steps to mitigate this. There also appeared to be a conflict for parents; on one hand their child has medical needs and as such requires adaptations, yet on the other hand, there was the desire that the children did not feel different, and instead blended in with their peers. Sarah talked about how she felt it was schools' responsibility to mitigate some of this conflict and to give Joe somewhere to belong. She pauses as she talks, carefully choosing words that reflect Joe's experiences. This is a common theme throughout Sarah's interviews and might reflect her experiences of having to use the right words in order to receive help for her children.

And um [pause] that was quite hard... on him. Um, and then they, we, we, we spoke to them a lot, at length, about how different [child] felt from other kids and how he needed more support in school. Sarah (Joe's interview) lines 234-235.

For Morgan's parents, it was a profound realisation that the pathway they always thought he would take was unlikely to be available due to the adaptations needed – the concerns stretched beyond belonging in the here and now and were felt when considering the future too.

'Because you have to make a plan as to what you're going to do, and all his friends were going on about doing A levels and going to university. And for [child] it was like, I don't think that's – I don't know, what am I going to do?' Sophie and Ian, Lines 780-782

For both families, it was felt that having a chronic illness had a significant impact on the self-esteem of the young person. For Sarah and Ian, there is almost a sadness as they reflect on the impact being chronically ill has had on Morgan. There is a suggestion that they may not have realised just how impactful the feeling of inadequacy is, and a guilt that as his parents, despite trying, they weren't able to help him realise just how much potential he had until he started college. This evidences how the stress of academic demands is far reaching and impacted both Morgan and his parents.

'But it's also quite distressing to him in, that the school that they were at, is very high performing, the children are expected to do very well. and I don't think [child] realised that it's not until he's gone to college in the last two or three weeks that he came back the one day he went, 'I really am quite good at things, you know', and I said, 'well of course you are', and he said, 'but I always felt like I couldn't do stuff, I always felt like I was failing'. He says, 'I'm actually - I've realised that I'm quite able'. Sophie and Ian, lines 359-365.

Sarah echoes these feelings, again indicating that the focus is on academic achievement, with little regard given to social and emotional needs.

> *'I think the hardest thing to get across to schools, is the impact it has on her self-esteem and on making friends and keeping them, because they don't seem to understand how hard it is'* Sarah (Emily's interview) lines 248-251.

3.3.2 Friendships

For all the participants, friendships were seen as the cornerstone of importance for the children, yet all parents expressed frustration and sadness with the difficulty the children experienced building and maintaining friendships. Sarah's frustration at the schools' lack of focus on friendships was evident.

> *'Yeah, but I don't think schools, I think generally the schools don't realise quite how important friendship…I don't think they realise quite how vital having those secure relationships are in school, for their wellbeing and their learning and their social learning, and the way their self-esteem and how they feel about themselves.'* Sarah (Joe's interview) lines 533-537.

Similarly, Morgan's parents joke about the lack of time Morgan has been able to spend with his friends, almost as if to suggest thinking seriously about the impact on his friendships and the loss he has experienced would be too much for them.

> *'**Interviewer:** [Child's] friends… how do you think they see [child]?*
>
> ***Dad:** [long pause] they don't. [all laugh] They hear him on discord*. [yeah, all still laughing].'* Sophie and Ian, line 984.
>
> *Discord is a free online voice, video, and text chat application.

Both parental reactions suggest that there is sadness when they think about the experiences their children have had. Sarah's may also indicate that she feels school is almost emotionless, focused on achievement, rather than wellbeing. Her reaction also indicates she feels dismissed by the school when she tries to explain her worries and fears about the children's lack of friendships.

3.3.3. Managing my own emotions

For the parents, there was a significant emotional impact of the experiences. The parents talked about the guilt, anger and loss that they felt for their children, and the experience of trying to consolidate this. Sophie and Ian in particular appeared to be in the grief cycle, and still very much experiencing loss regarding Morgan and his school experiences.

‘I think I feel sad that he can't do what other people can do I think it's really [long pause] sad isn't it? [yeah]…I feel cheated for him I suppose.’ Sophie and Ian, lines 1077-1080

For Sarah, the battle scars from advocating for her children are prominent, and unlikely to fade anytime soon.

‘Yeah, all my friends think all I do is go on about schools. [laughs] I reckon I've got PTSD when it comes to schools because it's just traumatic [laughs].’ Sarah (Emily’s interview), lines 763-769.

Knowing whether they were making the right choices on behalf of their child was something that all the parents grappled with. There was often an inner conflict as to how much the parents should be doing, and when they should be stepping back and allowing the children to experience events themselves. Sarah talked about the difficulty of letting things go and placing trust in the school – she references the leftover scars from previous battles clouding her vision.

‘I worry I'm not doing enough as her parent a lot, I worry that one day I'm gonna look back and think I should have done that sooner. I should have got that help sooner, but then I also worry that, Am I seeing things that aren't there because of what's going on with her brothers and stuff, so it's a bit of a… [long pause] It's hard. It's hard to know if I'm doing it right or wrong, I just have to trust that the school will pick up on it if she's not. Yeah, they seem to think it's okay so.’ Sarah (Emily’s interview), lines 550-556.

For Sophie and Ian, there was a questioning, as though they were looking for validation that Morgan should experience more than just school and home, even at the expense of attending school.

> *‘And you have to let him do normal things because it's part of being a young person, isn't it?’* Sophie and Ian, line 481

3.4 Superordinate theme 3: School isn’t for chronically ill children

For all the parents in this research, there was a distinct feeling that school is not set up for children who have a chronic illness, and that their children had greater difficulty than their peers in accessing mainstream education. This theme acknowledges the difficulty the parents have had with the education system.

3.4.1 The battles

For Sarah in particular, there have been significant clashes with school regarding the health and wellbeing of Emily and Joe. The impact of these battles on the family’s experience of schooling are evident as she talks. Sarah reflects on how she feels the school stigmatised the children because their chronic illness are invisible, and how she feels they are missing in the systems as a result. She speaks hesitantly, as though she is afraid to acknowledge she wishes her children were visibly disabled.

> *‘I often think if they had a different condition, they would be more supported but it's almost like because they're the more invisible kind of things there. [yeah] And they slip through the cracks, they're not supported properly. And I find that totally unfair, but I don't know how to, I know, and I know I can't explain how my experiences led me to that, it's just that is how it is. I know it is. If there were, if [child] was in a wheelchair and visibly disabled I'm sure they'd give away more support, but because it's sort of, [long pause] ah I don't know, I guess it's not so [long pause] it's, it's that middle line that she toes, you know she can be really well for quite a long time, and then not. And I think that's why it's because it's so variable I think that's partly why it's so hard to get the right support in place, you know, it's yeah.’* Sarah (Emily’s interview) line 630-341.

Sarah also talked about how there was an expectation that Joe would change his medical treatment to suit the needs of the school in order to continue attending, with the school going as far as using another pupil’s medical equipment. A desire to attempt to fit Joe’s medical needs into the school regime appears to be a theme that has continued through the different schools, and further highlights how Joe is not seen as the individual he is.

> *'Can you ask for a prescription for safety needles, and I was like no, he don't need them… they were literally like we won't have him. If he won't use the safety needles because of our staff and needlestick and safety.'* Sarah (Joe's interview) lines 131-144.

Whilst Sarah has had continuous fights, Sophie and Ian disclosed they had only had one disagreement with the school; however, they allude to the fact that this is due to their experiences with their older child, and the school's knowledge that they will do whatever it takes for their child's needs to be met.

> *'Umm, and I think probably because for us, we'd already had quite a battle to get the support our eldest needed with them, hadn't we? [yeah, yeah]. So actually, they might have either realised that we weren't going to back down, [laughs] or they thought actually we recognise this. Yeah, we said, they listened, as opposed to before where we said and we had to fight for it, whereas this time we didn't.'* Sophie and Ian, lines 258-264.

3.4.2 Systemic issues

For both families, a large part of their difficulties came from systemic problems with local government decisions. It highlighted a bigger problem with systems not having adaptations for children who are chronically ill. Sarah reflected on how government pressure on the school in turn led to pressure on both her and the children. The emotion as she talked is evident, as she reflects on school policy ostracising Emily further.

> *'So, if they all, all the class got good attendance, I think full attendance, they got a classroom award which would be a party of their choosing, so they could choose to have either [pause] uh, a sports party or a or a film party or something at school… so that was when she started to have problems fitting in at school - she'd have time off and then they'd all be cross with her, and then people didn't want to be her friends [trails off] Yeah, so that was hard.'* Sarah (Emily's interview) lines 87-100.

There is also a question over a lack of consistency between government and school policy, and the frustration felt by Sarah as she tries to get Emily's needs recognised and accounted for, echoing her earlier comments about certain conditions being the ones that receive support, possibly suggesting she wishes Emily was sicker, as she would then automatically receive the support she needs.

> *'It's been really hard, I keep, I feel like [pauses, stumbles over words a little] [Child] isn't disabled enough to be termed disabled, you know, in the eyes of, in the eyes of the school SENCo [yeah] so she's not on an EHCP, you know, but then she is disabled enough to get DLA and be, you know labelled that way, but not an EHCP.'* Sarah (Emily's interview) lines 471-476.

For Sophie and Ian, there was frustration that the local council wouldn't recognise and support adaptations for Morgan to remain in a school that supported him, alongside his social network. Consideration may also be given to social class and access to support, with Morgan's parents being able to pay to meet his needs.

> *'And she said, uh, put him in a taxi and send him in a taxi for school, [yeah] and we were in one of these catch 22 situations where, because he's because he's ill and he couldn't go to school because of his illness, the council should fund it, but the council wouldn't fund it, because he wasn't at his nearest school… So, we just bit the bullet in the end, and we started sending them by taxi.'*

The UK wide issue of exams were also raised, reflecting a system that works predominantly for healthy children, with those who are chronically ill at the mercy of exam organisers.

> *'But the other thing you're always wary about with [condition], is our exam system doesn't exist, uh, doesn't, doesn't fit with the [condition] pattern because you've got no control over where your exams are. So, if you, if you get your exam timetable and this is exam week, and you've got [condition], If you've got your maths and your English. On Monday, and you've got two exams on a Monday. Yeah, whatever you've got on Friday, you're going to do crap at... Despite the fact that in the pre-test he's been getting A*, A*, he's gonna be rubbish, you know'* Sophie and Ian lines 164-182.

3.4.3. Being left out

The parents talked not just about the practicalities of the school day for the children, but also the fact that the children were having to miss out on exciting, additional experiences because of their illnesses. Staff were often reluctant to include the children for fears about their health and safety, despite encouragement from parents. Sarah in particular talks about her frustration at the lack of willingness to even try, her laughter indicating a lack of belief in the school's reasoning.

> *'And she couldn't join in with things like swimming because they wouldn't put a one to one in the water…and she hasn't been able to do food technology for similar reasons. Safeguard, you know, health and safety concerns [laughs], which is really sad, because that would be her probably favourite lesson.'* Sarah (Emily's interview) line 252-258.

3.4.4. The punishments

For Sophie and Joe, their school experiences so far have been marred by experiences of being punished for having chronic illnesses. Sarah talked in depth about lack of staff understanding leading to punishments, and even what she perceived to be medical negligence. She stumbles over words as she talks, highlighting the emotion in the experience.

> *'He's got a sensor, so he doesn't need to have the blood tested in his fingers, unless it says he's high or low, and they've literally made him do it in his fingers all day it was like, and he said, this isn't right. This is not what my care plan says, and they were like, No, this is we're doing everything by the book we're doing everything, they were. And he said he wanted to phone me, and they wouldn't let him ring me, and that was it. I, I, I phoned up the local authority and said I'm going to remove him from the school because the safe - I think that's safeguarding, that's abuse you don't, you know, you don't need to unnecessarily give someone medical treatment that was just well out of order.'* Sarah (Joe's Interview) lines 195-204.

She reflected on how the children are also inadvertently punished, due to attendance parties, by being removed from 'fun' lessons for catch up intervention, or through being told they must do their medical interventions in breaktime to not disrupt the lessons, highlighting how it might be interpreted that education is a priority over Joe's medical wellbeing.

> *'I get really emotional every time because they are heart-breaking because they make it like it's their fault, and, [yeah], and they're being punished for something they cannot control. I mean they say they're not punishing them but by not giving them a reward [pauses, emotional]. How is that not a punishment?'* Sarah (Emily's interview) Line 289-299.

3.4.5 Home learning

For all the participants, the home learning impact of the Coronavirus pandemic was reported to have had a significant effect. Learning from home allowed the children to do so in a manner where they were able to rest, and work at their own pace. The impact was profound for Morgan's parents, but also devastating as they reflect on what could have been.

'I could, I can say, hand, hand on heart, I think, if [child] had had online lessons. Umm, for the whole of [long pause] his time, [mmm] he would have got more than five [GCSES]. [Yeah, he certainly could've] you know, and you know, he, he probably could have done everything.' Sophie and Ian, lines 344-346.

For Sarah, a similar impact was seen, however she was frustrated that the children's perseverance was only recognised when everyone was suddenly in the same boat, suggesting that she believes her children are treated as lesser than, despite the effort they put in to learning. It further highlights that Sarah believes school places value on academia alone, and it is only when Emily is given equal opportunity to participate, that her achievements are recognised.

'Um, In fact, she rarely got much sort of, ummm, sort of, well done, praise and stuff but since the lockdown learning that's been different, because suddenly she's getting letters like, um, saying that you're one of our, our work heroes and you're trying your best and suddenly we're getting, you know, brilliant engagement, top learner, all this stuff which we never have before.' Sarah (Emily's interview) lines 215-222.

3.8 The children’s experiences

The superordinate and subordinate themes for the children can be seen in table 6. The table also indicates whether the theme was present for each interview.

Table 6

Superordinate and Subordinate themes for child participants

Subordinate themes	Joe	Sarah	Morgan
Superordinate theme 1: The impact of relationships			
Relationship with staff	Yes	Yes	Yes
Peer perceptions	Yes	Yes	Yes
Superordinate theme 2: School as a system for change			
Following medical advice	Yes	Yes	Yes
The Emotional Rollercoaster	Yes	Yes	Yes
Wanting to be normal	Yes	Yes	Yes
Superordinate theme 3: The need for physical space			
Friendships	Yes	Yes	Yes
Covid & Home learning	Yes	Yes	Yes

3.9. Superordinate theme 1: The impact of relationships

This superordinate theme examines the children’s perceptions of staff, the expectations they place on the child, and their understanding of the children’s needs.

3.9.1. Relationships with staff

All the children talked about their relationships with members of staff in their education setting. The children all appeared to be cautious about building relationships with staff, and reluctant to let them in, indicating trust issues with the adults around them. Joe in particular talks about the pattern of being let down by staff, indicating that he now feels that adults need to prove to him that they are worthy of his trust.

> *‘That’s kinda the breaking point where I just didn't want to speak to any adults I didn't really know and trust. [mmm] So it took a long time after that… It took a while to rebuild that.’* Joe, lines 250-258.

3.9.2. Peer perceptions

Emily and Morgan found it difficult to consider how their peers perceived them, indicating that they have not contemplated that their peers may view them differently due to their medical condition. Joe on the other hand, had a very clear vision of how he was viewed by his peers: negatively. Joe struggles with the additional attention that he has due to his medical conditions and suggests that his classmates are irritated by the concessions he has due to his medical needs.

> *'And then I just go off because my blood sugars are high or low. and he's like, what is he doing, [mmmm] why does he get to go [shouting] and my teacher is just like, he's got a medical condition.'* Joe, line 75-78

3.10 Superordinate theme 2: School as a system for change

All the children talked about the emotional impact of being chronically ill in relation to education. This superordinate theme recognises the toll that being different in school takes on the children's wellbeing.

3.10.1. Following medical advice

For the children, there was a clear link between staff understanding their medical condition, and appropriate treatment and adaptations. Where staff had knowledge, they would often defend the child, and respond to their needs appropriately. Where staff had not taken the time to develop their knowledge regarding the child's condition, there would often be conflict. Morgan cited the experience he had with some teachers following periods of absence. He is tentative as he talks, alluding to the fact he feels he is an invisible member of the class, with school staff not even able to remember whether he was present or absent. Again, the focus on academics is clear, with the expectation that regardless of his attendance, he should be aware of and have completed schoolwork. It highlights school as a closed system, with its boundaries closed off to Morgan when he is not in attendance.

> *'Sometimes I wouldn't get the work from them [okay]. But was still sometimes expected to have done - it was slightly confusing.'* Morgan, lines 344-346.

The children all considered what their teachers might think of them, and whether that differed from their healthy peers. The children all identified that they would likely be considered differently. Joe's experiences linked back to staff knowledge, and he indicated that staff might think he is lying about his medical condition in order to get out of lessons.

'And most of them are okay with that there's a fair few that were a bit sceptical, so they said, go to, ummm, the medical bay.' Joe, lines 322-324.

Morgan uses humour to cope with the difficulties of trying to permeate a closed system, jokily stating that staff in school see him so little, that they would have little understanding of him and his needs. This might further highlight that Morgan feels school staff do not hold him in mind when he is absent from being physically present in school.

'They'd say who's [child]' Morgan, line 822.

The ridged boundaries of the school system were further highlighted when considering the standards to which the children were held. For all the children, being held to the same standard as their peers, despite not being able to match it was a significant issue, and the lack of concessions often caused emotional and physical distress. Joe took his reflections further and talked about re-joining class following a period in hospital, with the expectation he would just know what he needed to do, without so much as a welcome back, and an acknowledgement of his experiences. This experience may be seen to highlight his fight to be inducted into the school system, and the systems apparent failure to meet his needs.

'So, like back on the first day, I think, what would be best is for them to just come over to me explain what's happened and run me through what needs to happen.' Joe, lines 402-403

3.10.2. The emotional roller-coaster

Experiencing education with a chronic illness evidently includes highs and lows, and the emotions that go along with this. For the children, it was often a difficult experience, managing their own emotions, and trying to navigate the emotions of others. Emily talked about the experience of feeling guilt at letting her classmates down, but also the anger and frustration that she, and by extension her classmates, were being punished due to her condition. There is the suggestion that Emily attempted to block these emotions out to avoid the continuous roller-coaster of self-blame due to the inflexibility of the school reward system. She appears to have an internal battle between managing school expectations and rules and recognising that she pushes herself as far as she can with her condition. It may be tentatively considered that Emily is being singled out and blamed by both staff and peers for their lack of rewards, which subsequently will impact on her relationships with them.

‘Well, I don't really think about it at the time. But if the teacher mentions that we didn't get the points then I kind of feel like it's my fault. [You say that you feel like it's your fault, does that make you feel worried or sad or something else.] Well, if people mention it, it kind of makes me feel sad. But it's not really my fault because I do have [condition], so it's just my body.’ Emily, lines 323-328

Joe noted that the school system is unsure how to respond to incidents outside of learning and highlighted how he has to deal with a medical emergency, whilst managing the emotions of both his peers and his teachers.

‘I'd also want them to know that going out is just normal thing for me. [Yeah] And that, um, if I, if something happens, bad, then they shouldn't freak out and they should just tell me to go somewhere with someone. [mmm]. I'd feel like that'd be the best possible solution.’ Joe, lines 384-387

3.10.3. Wanting to be normal

Although all the children appeared to accept their reality and had adapted to managing education with a chronic illness, there still appeared to be a yearning to fit in with their peers, and subsequently the school system. Joe talks about how he would ignore his medical alerts in an effort to stay in class with his peers, suggesting he will be excluded from his peers and learning further if he removes himself for medical treatment. This could be interpreted as Joe not wanting an invisible child and wanting to remain present in the mind of his teacher and peers. This highlights that for Joe, the benefits of being present in class outweigh the risks of a potential medical event. He draws out the words as he talks, emphasising how much he doesn’t want to treat himself.

‘Although sometimes if I'm low, and it tells me that I'm low, sometimes I'll just try and like skip it, so I don't interrupt the class. Like, I won't scan because I'm kinda in that mental state already and I don't... want... to.’ Joe, lines 60-63

3.11. Superordinate theme 3: The need for physical space

When talking about their experiences, the children became most animated and talkative when exploring their peers, highlighting just how important they are to them. In particular, it was highlighted that online relationships were not enough – the children craved being physically present with their peers. This superordinate theme recognises that importance.

3.11.1 Friendships

For all the children, there was a longing for friendships and the support this brings in schools. However, due to the significant level of absences the children experience, maintaining that level of social support is evidently difficult, and the children naturally became excluded when they couldn't keep up the social expectations. Despite efforts to continue relationships online, Morgan spoke about how it did not replace the experience of being present in school, and how subsequently, he was often unintentionally left out. It highlights how the nuances of nonverbal cues are key cornerstones of developing relationships, and how these can often be missed when communicating online.

'Ummm, Sometimes I would have felt uhhh, excluded from the friend group. Because where I missed up, I missed uhhh, inside jokes and stuff like that.' Morgan, lines 631-634.

For Emily, her illness meant that she was seen as weaker by the other children, who took the opportunity to control her under the guise of friendship.

'Well, I didn't have too many friends in my last school because I had a friend that wouldn't let me play with my other ones.' Emily, lines 206-208.

3.11.2. Covid & home learning

For all the children, the change to home learning was significantly positive, and had a profound effect on their health and learning. For Morgan in particular, a move to online learning meant that for the first time in four years, he was able to take part in other activities outside of school, giving him his first taste of more common teenage experiences, and the ability to continue relationships face to face.

‘When it transitioned to online lessons with actual video from teachers. Uh It was, uh, probably the best school's being since probably primary school. So I've been able to do other things as well.’ Morgan, lines 477-480

Despite the positives of online learning, all three children stated that they would prefer to keep a blended approach to learning, citing their ability to be with their friends, highlighting the significant role friendships and social interaction play for these children. It also reflects that possibly for these children, school is not just a place for learning, it is a physical space where they are able to develop friendships, something that all three valued greatly. This could offer us some evidence of the desire for the children to be held in mind, and how being physically present is a key aspect of being held in the mind of both staff and peers.

‘In general I prefer being in school. So I get to actually see my friends in real life.’ Joe, line 469

4. Discussion

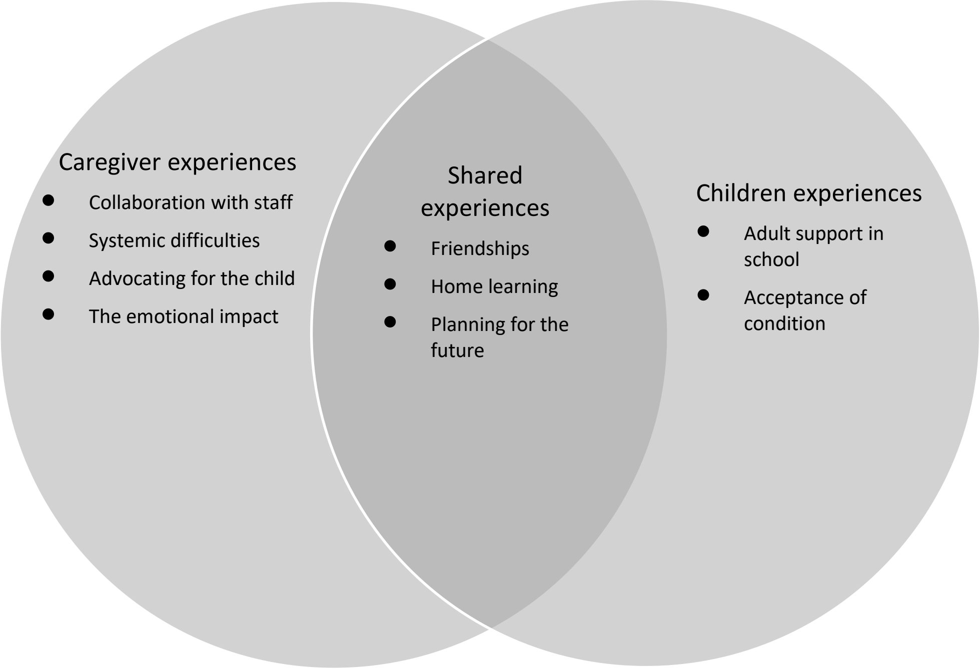
This research aimed to explore two research questions:

1. What are caregivers of chronically ill children's' experiences of education? And
2. What are chronically ill children's experiences of education?

Using IPA allowed greater exploration of these questions, with a more in-depth analysis than previous research. This section discusses the findings from these interviews in relation to (1) the research questions, (2) existing literature and (3) psychological theory. The discussion is split into parental and child experiences, before drawing together commonalities across the two groups.

Figure 4:

Overview of key discussion points



4.1. Caregiver experiences

One of the largest threads throughout the experiences described was how caregivers believed that strong relationships with staff, staff knowledge, and positive attitudes all influenced their children's experience of school. The families' experiences of this were notably different, with Sarah experiencing significant difficulty and breakdowns of relationships, whilst Sophie and Ian had a positive collaborative relationship with school, demonstrating possible variability between settings.

Commonality across experiences was the discussion of how a strong staff knowledge base led to significantly stronger collaboration, and therefore relationships between home and staff. Brook and Galili (2001) found that staff knowledge expanded as they had increased experiences of teaching chronically ill children. However, as was in Sarah's case, this can lead to staff feeling that once they have experiences with one pupil, they expect all pupils to present in the same way, raising the question of pupil identity, and being seen as the individuals they are (Yates et al., 2010). Duggan et al. (2004) found that even when staff knowledge regarding chronic illness and confidence in working with chronically ill children increased, their perceptions of these students being less able did not alter, indicating that further steps may need to be taken to break the perceptions of staff attitudes towards chronically ill children. In Ian and Sophie's case, personal experience was the catalyst to Morgan having significant levels of support in the classroom. Parents also talked about children being punished through a lack of understanding from staff, however, in Morgan's experience, his head of year had experience of the same illness, and this served as a protective factor. It might suggest that pupil experiences can be influenced by how teachers relate to the experiences the children are having (Angermeyer & Matschinger, 1996).

The parents' thoughts often moved to the influence that these experiences were having on the children. Though talked about as individual concepts, the links between friendships, self-esteem, belonging and missing out on experiences were clear. Sarah expressed her frustration at school taking an apparent lack of interest in supporting Joe and Emily in developing their friendships, which might raise the argument of where responsibility lies for social development. Education settings may hold the belief that they have set roles and tasks (Burr, 2015), and therefore may not hold the belief that it is schools' responsibility to develop social skills (Jones, 2001), despite research suggesting there is a role for teachers (Hollingsworth & Buysse., 2009). Research suggests that children with chronic illness can have difficulty maintaining friendships when compared to their healthy peers (Sentenac et al., 2013), however the importance of friendships for chronically ill children should not be underestimated. Strong friendships can lead to better medical adherence (La Greca et al., 2002), increased self-esteem (Varni et al., 1992), and a stronger sense of belonging and inclusion (La Greca et al., 1995).

Parents often fell into talking about the experiences of their children. This is not unexpected, when considering the role of the parent to often be to advocate for their child (Siegle, 2008), and particularly when considering the desire to protect a child with a chronic illness, due to the additional level of need they may have (Kratz et al., 2009). All the parents referenced difficulties in getting the children's conditions diagnosed, and it is likely that they have become used to speaking on behalf of their child when working with both medical professionals and school and fighting for both their and their child's voices to be heard (Rafferty & Sullivan, 2017).

For the parents, there was evidence that there were barriers and difficulties with their child accessing the right support, and consideration being given to their needs and abilities. Parents often reported difficulty in school understanding the medical needs of the child. A distrust towards parents was evident with Emily and Joe's schools seeking additional medical information from someone they perceived to be an expert (Lightfoot et al., 1999). There was often the suggestion from parents that they felt staff perceived children with medical needs to be inconvenient, and not fit into the school routine/system. Previous research has suggested that this may often be due to staff concerns regarding meeting the needs of the child (Duggan et al., 2004) or the need to spend extra time supporting these children (Olson et al., 2004). This might also be understood through social exchange theory (Thibault & Kelly, 1959; Emerson, 1962; Blau, 2017) whereby staff may choose to not pursue relationships where the cost may outweigh the benefits – namely that the teacher may feel they are having to put more into the relationship then they receive. Social exchange theory (Thibault & Kelly, 1959 ; Emerson, 1962; Blau, 2017) also recognises the power imbalance that is present in these relationships, and how the adult may have control over the child having their needs met, as evidenced through Joe's experiences of having treatment denied in school.

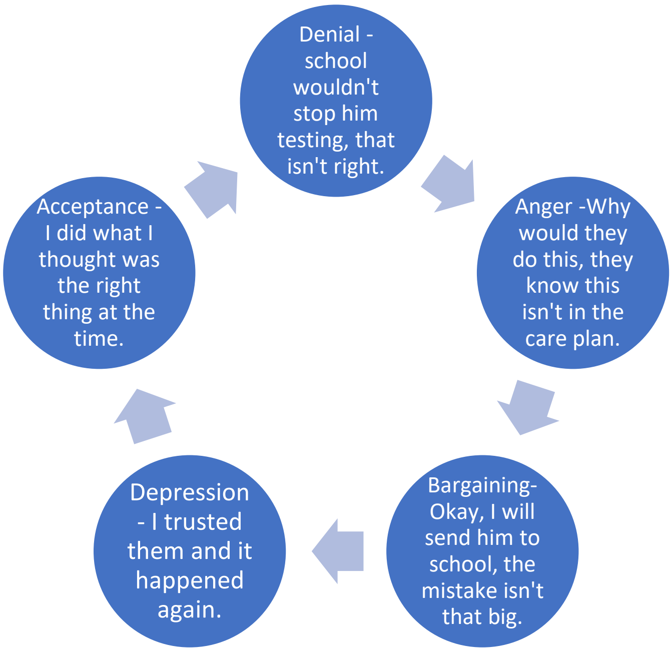
Systemic issues were a significant barrier to children receiving support, with schools often governed by local or national authority guidance, which may not offer the flexibility required. Pressures on school to achieve good standards of attendance often led to processes that further ostracised the pupils (UK Government, 2007). It may be argued that ill children could 'skew' attendance and performance data, amplifying the apparent need from schools to keep the disability invisible. It is difficult for staff to affect change until the larger systems change, and therefore it might be suggested that at a systemic level, the disadvantage the children are facing is being reinforced (Bronfenbrenner, 1977).

Inconsistencies across systems often led to confusion and difficulty for Sarah, with her noting Emily was eligible for Disability Living Allowance (DLA) but not an Education and Health Care Plan (EHCP). This created a level of tension, whereby Sarah appeared to believe that school staff felt that if Emily was 'really ill' she would be in receipt of an EHCP, and therefore may have misattributed her difficulties to things such as lack of effort (Kelley, 1967; Ross, 1977). Similarly, the theory of circular causality (Dowling et al., 2003) may be helpful when considering these experiences as teachers may believe you have to have an EHCP to be unwell, and as Emily does not have an EHCP she cannot be unwell. Within this, there is also an element of power and hierarchical organisation to consider, as well as what an EHCP represents to the system. The school system became closed to Sarah and her concerns (Dowling et al., 2003), and rather than work collaboratively to address Emily's needs, opted to make a unilateral decision on access to support. From the parental experiences, a power disparity regarding resources was highlighted. Sarah noted how she did not receive support from school until she involved outside agencies, and often had her requests for EP involvement dismissed. Sarah also spoke candidly about feeling as though she has 'PTSD' from the continuous fight to access support for her children, and the perceptions she feels school have of her (Kelley, 1967), whereas Ian and Sophie felt that in the Grammar school, there were numerous resources to support Morgan. Tentatively, consideration might be given to the differing experiences of the families through the lens of social class and access to support, and the role of inequality in education (Delaruelle, van de Werfhorst & Bracke., 2019; Popham, & Iannelli., 2021). There is a role for EPs to support enabling dialogue here (Gameson & Rhydderch, 2008), which will be explored further in section seven.

Parents talked within this research around carrying a multitude of emotions. It might be helpful to consider the parent's emotional experiences in the context of the grief cycle (Kübler-Ross & Kessler, 2005). Though this is usually associated with death, it can be used to frame the ongoing emotional rollercoaster that parents of chronically ill children feel (Penzo & Harvey, 2008). The grief cycle can be considered to restart when the parents experience a new event or crisis, or when their child does not experience the milestones one might expect. This was evident as parents talked about their child's experiences. Figure 5 evidences a grief cycle described by Sarah. Understanding and support from professionals around the family can lead to better emotional support for the parents, increased collaborative working and more effective outcomes for the young person (Penzo & Harvey, 2008), which seemed to be lacking in some of the accounts given in this research.

Figure 5

Example of the grief cycle for Sarah



Ian has the same diagnosis as Morgan and would often talk about his personal experiences through the interview. It is possible that Ian was looking to contextualise his understanding of Morgan's experiences, but it may also indicate a lack of acceptance that his child now faces the same difficulties he does (McAllister et al., 2007).

Distress in parents of chronically ill children is not a new phenomenon, as they experience events that parents of healthy children typically do not (Hauenstein, 1990). Burnout for parents of chronically ill children can be understood by the experiences of Sarah, who is hypervigilant when considering her engagement with schools (Lindström et al., 2010). Critically, it is important to note that the grief cycle is presented as a 'neat' process, which does not always reflect the complexities of emotions (Stroebe et al., 2017).

4.2. The children's experiences

The impact of the adults around the child was significant for the children in this research. For Morgan, the impact of having a knowledgeable support system in school meant that he had an advocate and someone to rely on. For Joe, incident after incident led to significant distrust in adults, and the suggestion that he had to fend for himself.

Positive relationships with staff are vital for fostering positive peer relationships (Sentenac et al., 2013) and engagement in academic learning (Bruce et al., 2008). Staff often have fears about how they should best meet the needs of the child, as is evident by Joe's experiences (Prevatt et al., 2000; Gómez et al., 2020), and though training can alleviate some of these worries, it still does not account for the perception staff have of chronically ill children, and how this may influence their engagement with them. It might be argued that for staff it can be difficult to think of an ill child, when the role is to support them to thrive (Burr, 2015).

Knowledge of the chronically ill child, (or lack thereof) meant that staff held the same expectations as they did with healthy peers. Whilst this went some way to encouraging children to reach higher levels of attainment (Hilliard et al., 2015), it also caused conflict when the children were unable to meet these standards (Bruce et al., 2008). The children often reflected on how staff found it difficult to recognise and adapt to their needs, be this providing work, or acknowledging hospital admittances the child had experienced when they returned to school. Consideration might be given as to how the teachers' discomfort regarding the children's medical needs could often lead the children not feeling 'seen' (Duggan et al., 2004). Joe in particular noted difficulty with reintegration following periods of illness. This highlights their experience of the school as a closed system, and Joe as an invisible child (Dowling et al., 2003). This was also noted by Morgan highlighting an expectation that he would have completed work he had not been given.

The children often declined to explore feeling different to their peers, or to talk about the loss of experiences they have had. It could be inferred from this that the children chose not to engage in this line of questioning, as 'leaning in' to these experiences would require acknowledgement that they are different to their peers (Lambert & Keogh, 2015). It might also be argued that the children declined to talk about these experiences to shield their parents from the difficulties they experience as often, the children and their caregivers spoke about the same experience, but provided contrasting views (Talwar & Crossman, 2011). Consideration may be given to the need for the school system to provide space for children to explore these feelings, and this will be considered under implications for practice.

4.3. Shared experiences

Friendships were noted by both parents and children as being of great importance, with Sarah noting how in her experience, the difficulties with friendships caused significant distress for her children, more so than missing out on learning. Similarly, the children spoke at length about friendships, more than any other topic throughout the interviews. This is in line with findings that suggest strong peer relationships are significant for children with chronic illness and are often a prerequisite to engaging in academic learning (Varni et al., 1992; La Greca et al., 1995; La Greca et al., 2002). Peer acceptance is also noted to be of greater importance than parental acceptance in adolescence, and increases self-confidence, medical adherence, and acceptance of the diagnosis (La Greca et al., 1995; Olsson et al., 2005; Scholte & Van Aken, 2020).

For all participants, home learning was credited as having had a significant effect on their experiences of education. Learning from home often alleviated worries about children's medical treatment, giving participants greater capacity to engage in their online learning. Being able to learn at their own pace, and recap previous learning was noted as a significant benefit by the children (Masters & Gibbs, 2007). For children with chronic illnesses, time off school can impact on learning, due to gaps in basic skills and the use of the spiral curriculum (Ireland & Mouthaan, 2020). The development of remote working may also provide an opportunity for the children to join in with learning when at home or in hospital (Fels et al., 2001), something Joe would have appreciated.

Parents spoke with some trepidation regarding the future for their children. There are a significant number of unknowns, which can make it difficult for families to know what to expect or plan for (Batchelor & Duke, 2019). Sarah's account of not thinking that far ahead, could reference a wider worry of parents of chronically ill children, namely that the unpredictability of the medical conditions can make it difficult to know what the young person's future looks like (Nuutila & Salanterä, 2006). It may also reference the significant emotional demands from being a parent of a chronically ill child, and that for her own self-preservation, she focuses on the here and now (Lindström et al., 2010).

The children, overall, had some difficulty thinking about their hopes and dreams for the future, with both Emily and Morgan being unable to give much substance to their hopes for the future. Joe on the other hand, had strong aspirations of what he wished to achieve. For Emily and Morgan, both sets of parents had lower aspirations for what they might achieve, whereas Joe had a parent who shared high aspirations. Parental aspirations for their child can have a significant impact on the child's academic self-concept and is possibly evident here (Buchmann et al., 2022). It may also be that parents are afraid to encourage the children to have high expectations and project these lower attainment goals to shield both themselves and their children from experiencing further loss and disappointment (Wolman et al., 2001).

5. Psychological theories relevant to this research

5.1. A bioecological systems perspective

A consistent theme from this research was that the experiences of both caregivers and children was embedded in a systemic context. Table 7 attempts to evidence some of the systems from these participants' experiences, using Bronfenbrenner & Ceci's (1994) bioecological model as a foundation.

Table 7

A bioecological system perspective of the participants experiences

Systemic level	Systemic aspect	Context of the study
Biosystem	The Child	The children and their experiences are central to the system.
Microsystem	School staff	School staff featured heavily in participants' recounts of their experiences and were often key when considering whether experiences in school were positive or negative.
	Friends	Friendships were a significant concern to both parents and children and were affected by the children's chronic illness.
	Family	Incidents in school had a direct impact on the family, with Sarah in particular talking about moving the children's schools.
	Healthcare professionals	Though perhaps usually placed in the Exosystem, these families had far more involvement with medical professionals then healthy children.
Mesosystem	The interaction between the Microsystem and the Exosystem	Support from school staff often led to better understanding of the young person amongst their peers.
Exosystem	Other parents	Judgement from other parents often led participants to question their decisions.
	Peers	Peer opinion made a significant difference to participants. Peers were on occasion supportive of the child's illness but could often be judgemental and disbelieving.
Macrosystem	Local authority systems	A significant issue for participants were barriers that were placed due to local authority policy or process.
	Education laws	Education laws were also of significant difficulty for participants, particularly considering school attendance and exams.
	The NHS	The NHS, treatment and hospitalisation were all regular experiences for participants, and often frustrating.
Chronosystem	Transition	Experiences in prior schools appeared to directly influence participants' hopes/fears about moving to new education settings.

	The future	Experiences within systems made it difficult for participants to think towards the future, instead focusing on the here and now.
	The child's health	The children's health was noted to change over time, and this impacted on the experiences of both the children and their caregivers

5.2. Maslow's Hierarchy of needs

It may also be helpful to consider the children's experiences in the context of Maslow (1943).

Table 8

Participant experiences in the context of Maslow's Hierarchy of needs

Level of the hierarchy	Experiences of the participants	Implications
Physiological needs *Food, water, warmth, rest*	Due to their medical needs, the children often attended school with limited rest, and some referred to difficulty eating.	Reasonable adjustments such as access to quiet areas, and opportunity to eat in school would likely be beneficial.
Safety needs *Security, Safety*	The participants talked about potential cases of medical negligence or neglect indicating their safety needs were not being met in school.	Having a key, trusted adult to go to in school would be beneficial. Further training for school staff may also be helpful.
Belongingness and love needs *Intimate relationships, friends*	The children and their caregivers expressed concerns around the children making and maintaining friendships. Joe referenced his difficulty maintaining relationships with adults.	Opportunity for development of a relationship with a key adult, or the use of social skills groups may be beneficial. Adaptations to ensure support when the child is off school would also develop a sense of belonging.
Esteem needs *Prestige and feelings of accomplishment*	The children not receiving praise, or having low self-esteem were concerns noted by caregivers	Praise for effort and engagement. Given opportunities to succeed.
Self-actualisation *Achieving one's full potential, including creative activities*	Caregivers expressed concerns that children were not reaching their full academic potential. The children noted they often missed creative or fun activities for interventions.	Difficult to reach due to the potential gaps in the earlier stages of the hierarchy. Opportunity to engage in creative activities instead of intervention would be helpful.

6. Strengths and limitations of the research

Table 9

Strengths and limitations of the research

Strengths	Limitations
● This study gave the opportunity for both caregivers and young people to talk about their experiences in depth. ● IPA allowed for their experiences to be critically interpreted and explored in ways that have not previously been. ● Data was gathered using semi-structured interviews, though the researcher generally followed the participants 'story.' Participants were interviewed via Zoom from the comfort of their own homes, to allow them to talk as freely as they wished to. As per the methodological aims of Smith et al. (2009), open ended questions were utilised to empower participants. ● The use of 'face to face' interviews allowed the researcher to identify the nuance in how participants spoke, as well as their body language and emotions. This was used to support the linguistic analysis and interpretation carried	● The samples in this study consisted of the views of only two families, which may make it more difficult to generalise. ● Whilst the research wanted to focus on the views of caregivers and the young people, caregivers on occasion would talk about their child's experiences, creating a 'triple hermeneutic.' The researcher was aware of this during data analysis and made every effort to focus on the participants interpretation of events, not their perception of their child's interpretation of events. ● IPA's approach to data collection means that the researcher is involved in the construction and interpretation of the information shared, both through data collection and analysis. This does mean that the researchers' own experiences may have influenced the interpretation and therefore the results of this study. The researcher utilised supervision, a research diary

out by the researcher, adding richness to the ‘stories’ of these participants. ● Though the interviews consisted of families from England, it might be suggested that the findings are generalisable across all four nations of the UK, due to the focus on the social-emotional needs of the children and caregivers, rather than the nation-specific education systems.	and reflection to consider how they may have influenced the research, and how the research may have influenced them. ● Recruitment for this study took place in very limited locations. This will have meant that only those actively engaged with social media will have had the opportunity to engage in the research. ● The children in this research were given the opportunity to interview alone, or in the company of their caregivers to help them feel more at ease. Joe chose to interview alone, and spoke at great length about his experiences, whilst Emily and Morgan interviewed in the presence of their caregivers, and often gave shorter answers, or looked to their parents to speak for them. This may be due to previous experiences of having parental advocation or due to a want to protect their caregivers from their true experiences of being chronically ill in school. Whilst ethically this met the needs of the children, consideration may need to be given as to whether the views in this research are truly that of the young person. This is reflected on in

	part three of the thesis. Research in the future may wish to identify ways of meeting participants comfort whilst maximising opportunity to explore their lived experiences.

7. Considerations for Educational Psychologists' practice

This research has theoretical generalisability (Smith et al., 2009; Smith & Shinebourne, 2012) and the experiences of these families reflect the current literature that exists on the experiences of chronically ill children. Through this research, the need for Educational Psychologists (EPs) to work with chronically ill children has been highlighted.

A clear theme was the difficulty caregivers experienced in permeating the school system, which often appeared to be a closed system. EPs have a unique contribution to offer through using consultation (Wagner, 2008) to enable dialogue, explore constructions, and help both school and home to reflect, reframe and reconstruct (Gameson & Rhydderch, 2008). EPs may also be in a strong position to help mediate when there is conflict between home and school system. EPs may also find themselves in a position to work systemically with the school to explore and change policies such as the attendance parties mentioned by Sarah and Emily. EPs may also find themselves in the role of 'link person' between home, health, and education, and as such in a position to enable dialogue here.

EPs are also able to use their knowledge of psychology to develop the school's understanding of the children's needs, and to upskill staff as appropriate. Though not reportedly recognised by the schools of participants, EPs are able to provide holistic assessment regarding the needs of the child (BPS, 2015), which may be helpful in school adapting practice, or implementing strategies to support them in their learning and emotional and social wellbeing, as children with chronic illnesses appear to need intervention and support in order to reach their potential.

Children also appeared to be lacking a key adult in school, which may be a prerequisite to them feeling safe and secure (Maslow, 1943). Careful consideration may need to be given when working sensitively with children who have experienced difficult or traumatic life events. Wynard et al. (2020) identifies that EPs can conduct this work with children themselves or upskill others to support the children under their guidance, as one role of the EP is to delegate work under their supervision (HCPC, 2016). The use of ELSA's in schools to provide emotional support is common (Krause et al., 2020), and schools may be supported to help meet the children's needs through ELSA sessions, with the EP providing supervision and guidance on meeting the children's needs (Osborne & Burton, 2014). This research has highlighted the need for children to have a safe space to share their thoughts, feelings, and experiences.

8. Future Research

Future research could include:

- Research that seeks the views of parents, the young person, and teachers to understand the perspectives of school staff when looking at the same phenomenon.
- A study that may examine the child's learning and cognition to help frame parental views (previous research has all relied on parental report).
- A similar study that is split into smaller age ranges, such as primary, KS3 and KS4 to allow for a more heterogeneous examination of the phenomenon.
- A similar study that includes intersectionality of conditions such as Dyslexia or Autism Spectrum Disorder (ASD).
- A similar study that explores experiences from across the world to explore how cultural norms may influence how chronic illness is perceived and supported.

9. Summary

This research has explored the lived experiences of chronically ill children, as well as the experiences of their caregivers in relation to education. The research questions were (1) what are chronically ill children's experiences of education? And (2) what are the caregivers of chronically ill children's experiences of education? Participants spoke openly and transparently about their experiences, sharing the highs and lows of educational experiences. Key findings included the importance of relationships and open communication, the benefits of blended learning, systemic barriers to change, and the emotional impact on both caregivers and the young people. This research highlights that the needs of children with chronic illness are still not fully understood by schools, and that experiences can vary significantly. Implications for practice include using consultation to bring together caregivers and schools to facilitate change, upskilling school staff to meet the needs of chronically ill children and providing children with a safe space to explore their feelings.

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Chronically ill children and their caregivers’ experiences of education: an interpretive phenomenological analysis

Part three: Critical Appraisal

Wordcount: 6728

Part Three: Critical Appraisal

1. Introduction

This critical appraisal is split into three sections. The first section will examine the process used to identify the research project. I will then reflect on the exploration of the existing literature, and how I arrived at my research questions. Through this exploration, I will demonstrate my rationale for the study.

In the second section of this critical appraisal, I will reflect on the decision I took throughout the literature review. Following this, I will explore the considerations that influenced my methodological decisions and reflect on alternative methodologies which were considered. I will use this section to reflect on the selection and recruitment of participants, data collection, and the data analysis. Ethical considerations that arose from the research will also be presented and addressed. I will also consider my role as a researcher, and the impact this may have had on the research.

In the third section, I will consider what contributions that this research makes to existing knowledge. I will also reflect on how these findings may be developed further, and how they can be disseminated across the academic and public fields. I will also discuss what potential contributions to future research have been identified. I will conclude by reflecting on the implications for both my individual practice, and practice for educational psychology as a whole.

This section of the thesis is written in first person. This has been done to recognise my role as a reflective and reflexive practitioner. In doing this, I also recognise that I have been actively involved in the development of, and the practical elements of this research.

2. Rationale for the thesis

2.1. Inception of the research topic

The idea for this research came from both personal and professional experiences. I personally have several chronic conditions. I received many of my diagnoses as a young adult starting university, where it was relatively easy to access support and have additional measures put in place. I began reflecting on what might have happened had I received the diagnosis as a child, and the complexities of accessing support when in school. I became curious as to what support exists, and what the experiences might be of families who have children who are academically able but might find it difficult to access the curriculum or who might miss large sections of their schooling due to illness or hospital appointments.

This interest was further piqued when during my second placement, a school raised a child who they felt I needed to be aware of. They explained he had a heart condition and regularly missed school because of this, but they were not sure how to support him as he was academically able when he was attending school. This led me to consider that there was a subsection of children with needs that school may not know how to support. My curiosity in this topic deepened when during a training section on the new Additional Learning Needs and Education Tribunal (Wales) Act 2018 (ALNET; Welsh Government, 2018), it was referenced that there was expected to be a closer working relationship between health and education, suggesting that supporting these children who had chronic health conditions was likely to soon be a more prominent part of my role.

2.2. Identifying and exploring gaps in the literature

My initial brief literature search found a plethora of research on chronically ill children. Much was focused on the academic, social, and emotional gaps between chronically ill children and their peers (Currie, 2005). There also seemed to be significant research on the experiences of the family unit, and that of healthy siblings (Gan et al., 2018; Ernst et al., 2020) Often, research looked broadly at the parent experiences of caring for chronically ill children, (Owoo, 2017) or their perceptions of their child’s wider experiences (Benson et al., 2017; Castro et al., 2020). Research also looked broadly at children’s experiences of having a chronic illness, and the impact that it had on their social and emotional wellbeing (LeBlanc et al., 2003; Barrera et al., 2005)

Further research identified that some literature existed that has subsections considering the educational experiences of caregivers in particular (Bowtell et al., 2018; Marks et al., 2021). Several papers were identified that focused solely on parental views, those that did consider children's experiences but focused on specific conditions, and others that used questionnaires to gain the views of caregivers and the children (Freckmann et al., 2018)

Little of the research was UK based, and that that was, focused on singular conditions, and were often more than a decade old (Dyson et al., 2007; Dyson et al., 2011). My literature search identified that there is a gap of up-to-date literature that (1) explored the experiences of both the young person and their caregiver, (2) was UK based, (3) was viewed through the lens of an educational psychologist, and (4) used interpretive phenomenological analysis (IPA) to dig into these experiences.

2.3. Development of the research question

This research had two questions, (1) what are chronically ill children's experiences of education? And (2) what are the caregiver's of chronically ill children's experiences of education? I found that the research questions developed naturally. I wanted to explore the experiences that both the caregivers and the children had, without placing a prescribed direction on where the research would go, instead allowing for it to be taken wherever the participants chose to take it. This naturally suited the exploratory research that I intended to undertake.

Naturally the research question arose from my methodological stance, as well as being directed by the current literature, and the identified gaps. The decision to use IPA came from the research topic, but also a desire to really interrogate the research, and pick apart the experiences of the participants, ascribing meaning to their lived experiences. IPA is a method that encompasses these approaches, and therefore was the most appropriate approach (Smith et al., 2009).

3. Critical account of the development of the researcher

3.1. Conducting the literature review

Knowing where to begin with conducting the literature review was a difficult process, not least because each piece of literature had different definitions of what was meant by a chronic illness. In order to proceed with the literature review, I first had to spend some time identifying my own definition of chronic illness. I found that this approach stemmed from my own personal experiences and ideas regarding chronic illness, as well as reviewing numerous sources to help identify common factors across different services such as the NHS (NHS Wales, n.d.), and in academic articles (Dowrick et al., 2005). I also considered what might be helpful to include in the literature, reflecting that I did not need to limit literature to specific illnesses, instead including all papers that referenced chronic illness in line with the fairly homogeneous experiences of individuals being their experiences of education whilst chronically ill, rather than a specific condition.

I chose to split my literature review into three sections. A narrative style approach to the literature, a systematic style approach to the literature, and finally a discussion that drew conclusions from both sections together, identifying the current gaps in the literature. This was advocated for by Boland et al. (2017). I utilised this approach, as I had spent some time grappling with what should or shouldn't be considered relevant to the research questions. Splitting my literature review in this way allowed me to contextualise the wider experiences of chronically ill children and their caregivers, before honing my approach to focus purely on the experiences that they have in relation to education.

The database search returned a significant amount of research papers, however a more detailed inspection found that a large majority of these papers were duplicates. Further interrogation of the data also eliminated papers that referred to education in the sense of 'being educated' rather than school experiences. Papers written in a language other than English were excluded, though this only accounted for a very small subsection of papers (<10). I did reflect on what this exclusion meant for the generality of this literature review, as by using English only papers I was narrowing the scope to mainly Western countries.

However, it might be argued that this was in keeping with the scope of the research, and therefore appropriate. This was also acknowledged as a limitation within the literature review section, and a possible area for future research.

The literature review was a task I approached with some trepidation; however, I feel that the final product is a comprehensive and detailed piece of work. I feel that splitting the literature allowed me to provide a depth and breadth I may not have if I had focused on only a narrative or systematic type literature review. I feel that I was critical, yet balanced in my approach to the literature, and successfully evidenced a research gap, underpinned with what I believe to be a sound theoretical and practical rationale. I also reflect on how I have made significant strides to be transparent about the process used for sifting, as well as inclusion and exclusion criteria – this ensures that my process could be replicated and explored further if a reader wished to do this. I feel the literature review provides a strong overview of the current literature on chronically ill children and their caregivers, and later, their specific experiences of education.

3.2 Methodological considerations

3.2.1. Ontology and epistemology

Ontology and epistemology are not concepts that come easy to me, and I spent some time reading at length on these subjects to ensure I was confident in my choices. Guba and Lincoln (1994) was a particularly helpful read when contextualising what I wanted to research, and what my ontology and epistemology might be.

The aims of my research were to explore both caregiver and the chronically ill child's experiences of education. As such, I adopted a constructivist epistemology, underpinned by a relativist ontology. Adopting the constructivist epistemology recognised my belief that each individual's experience is subjective and constructed from their individual realities (Braun & Clarke, 2013). A relativist ontology compliments this constructivist epistemology, as it reflects my belief that the chronically ill child and their caregivers' experiences of education was subjective and could therefore be interpreted in several ways. I placed value on the fact that each participant would bring their own (equally valid) reality and perceptions to the interview, which would add richness to my research. I was also particularly excited by the prospect of interpreting participants' experiences of the same phenomenon, but from different perspectives.

In keeping with my ontological and epistemological stances, I opted to use a qualitative method, specifically that of IPA. As highlighted by Smith et al. (2009), IPA allows the idiographic nature of chronically ill children and their caregivers' experiences of education to be explored. The use of IPA also linked into my research questions examining chronically ill children and their caregivers' experiences of education which underpins the constructivist stance that each participant will have their own unique experiences, and their own interpretation of these experiences (Braun & Clarke, 2013).

3.2.2. Alternative methodologies

It has been suggested by Willig (2013) that the type of data collection and subsequent data analysis the researcher chooses to use is determined by their ontological and epistemological stances. This therefore suggests that had I adopted positions other than that of a constructivist epistemology and relativist ontology, I would have likely chosen different data collection and analysis methods.

The use of a positivist position, as an example of an alternative stance, suggests that there is an absolute truth or reality, with only one interpretation of what is being experienced (Willig, 2013). This did not feel appropriate with what I wanted to research, and my beliefs as a researcher – I wanted to be able to understand lived individual experiences of either being a caregiver for, or a child with a chronic illness in relation to education.

I considered whether a focus group, or questionnaires might have been an appropriate approach to data collection. However, I decided against both alternative collections for several reasons. For questionnaires, I felt that reducing the experiences of the participants down to Likert scales or open-ended questions would not give nuance to what they would be sharing. I was also concerned that by using questionnaires, I would be essentially 'pre-coding' the answers by asking only what I wanted to hear. Similarly, I feared in collecting data in this way, I might lose the individuality of participants. Focus groups were perhaps more in keeping with the approach I was taking; however, I was concerned that they may end up being led by one person, not giving credence to the others' experience. I also questioned whether participants would be willing to talk about potential emotive subjects in front of others.

3.2.3. Semi-structured interviews

I have previously conducted interviews as part of my MSc, and my small-scale research project, and as I have moved through my research career, I have built upon each previous experience. The interview schedule was helpful to have to hand to ensure some consistency, though participants often naturally covered the questions without me asking them. Using IPA did present some problems, as it was often difficult not to provide sympathy or direction when listening to emotive, and on occasion traumatic events the participants have experienced. I feel that I navigated these difficulties far easier with the adult participants than with the child participants. Whilst one child, Joe, spoke openly and honestly, Emily and Morgan were far more closed in their answers, and I found myself leading the conversation far more than I feel I realistically should have. However, I do feel that I was responding to the needs and wellbeing of the children by doing so. On reflection with my supervisor, I recognised that the children's closed answers were in themselves an opportunity for interpretation and analysis. This also provided me with space for reflection on the role of the EP, and what this might mean for my practice in working sensitively with children around life events. It also gave me pause for thought around the experience's children have, and who is listening to them, and reiterated the importance of rapport building, and scaffolding children to be able to tell their experiences.

The semi-structured interviews provided a rich opportunity for individuals to tell their stories. As touched upon earlier, they gave participants the freedom to lead me in whichever way they felt most comfortable doing whilst telling their story. However, whilst most interviews were under an hour, two of the interviews lasted for significantly longer, which led to me reflecting on whether this might mean that some individuals' stories are spoken to more than others.

3.3. Selection and recruitment of participants

3.3.1. Inclusion and exclusion criteria

The inclusion and exclusion criteria took some reflection and supervision to develop. I was aware that I had to be strict with my inclusion criteria, firstly to ensure I had an ideographic sample, but also particularly given the debate over what constitutes a chronic illness. I was also aware that I did not want to make the criteria so small that it made it difficult to recruit. I chose to go with children who were experiencing persistent absences due to their chronic illness, to allow for a variety of experiences, and more in-depth analysis. I was conscious that if a child was 'in remission' with their chronic illness, they would likely be experiencing school the same as that of their healthy peers. Having some disruption would allow for questioning around the support schools were putting in place. It is also of note that, even when well, children with chronic illnesses are likely to experience some disruption due to medial appointments. 90% or below is the government definition for a persistent or chronic absence from school (UK Government, 2021) so this is what underpinned my use of 90% attendance or below. I also chose to exclude neurodiverse conditions (such as ADHD or ASD) and specific learning difficulties (such as dyslexia or dyspraxia) as I wanted to (as far as possible) keep the homogeneity of the experiences the children and their families were having to keep the narrow scope of my research. I recognise that exclusion of these health conditions may be a limitation, and that further research into this intersectionality in the future will likely be beneficial. I chose the age range of 11-16 to try and have a relatively homogeneous group of children. On reflection, If I were to complete this research again, or if I were to further explore children's experiences, I may focus on a slightly smaller subscale, of KS3 or KS4, to make the experiences more homogeneous.

3.3.2. Recruitment

Recruitment proved to be far more difficult than I had originally anticipated. Lengthy discussions were held during supervision regarding where and how best to recruit families form (See Appendix T for supervision/reflective notes). Consideration was given as to whether to recruit from schools known to me through my work as a TEP, however I had concerns about how this would lead to recruitment from a localised area. I also reflected on the information I had gathered during my literature search, whereby it was noted that children/their families did not always disclose to school that there is a medical need.

Consideration was also given to using NHS hospitals as a means of recruitment, however the issues of localised recruitment and/or 'hand picking' hospitals and the NHS requirement for their own board of ethics to approve recruitment providing timing difficulties, led to the decision that this again, was unlikely to be the most appropriate method of recruitment. Further discussion identified that the use of national charities that did not focus on a specific condition, and the use of social media would allow me to access a greater number of participants with a variety of medical conditions and would circumvent the concerns regarding hand picking participants with specific conditions. From previous experiences of research, it was noted that typically charities did not require their own ethical approval if they were only circulating information on the study at hand, and I hoped that this experience would be replicated. I emailed many charities and contacted several social media groups. All but one of each declined, citing lack of capacity to facilitate recruitment, or not wanting to distress group members. Charities and social media groups were chosen based on their aims and objectives – namely that they supported children with a broad range of medical conditions or chronic illnesses. The one charity that did respond, was over the wall, a UK based charity whose aims and objectives are supporting children with health challenges and/or disabilities and their families. The social media group that responded cited their aims and objectives as to be a group for families where a child has a medical need or disability. The citing of not wanting to distress group members was a barrier I had not anticipated, as I did not perceive advertisement alone to be distressing for the participants. I had also given considerable thought to the ethics of my research (Appendix L) and provided a detailed gatekeeper letter (Appendix B). However, through having these experiences I learned about the complexities of recruitment and individual charity and social media group requirements requiring time and on occasion, additional ethical processes to protect the needs of their clients. On reflection, I can understand that the aims and objectives of a charity are to meet the needs of their clients first and foremost, and that all decisions gatekeepers take are around the ethics of protecting these clients. Should I conduct similar research in the future, I will ensure I allow additional time and space for these requirements, and/or seek to have a meeting with the charities/group admins to be able to discuss their concerns. One charity agreed to share the recruitment on their social media channels, and one social media group allowed me to promote recruitment via them.

One family was recruited from the social media group, and the other via email after seeing the recruitment poster on social media.

I had hoped to recruit a further family, and received some further interest, however one family declined to partake after further information was provided, and another parent wished to partake, however their child declined. Some consideration was given as to whether it would be appropriate to interview the caregiver alone, however I decided it was unethical to interview the caregiver after the child had expressed their wish to not partake. A relaunch of recruitment in October 2021 (in line with the original ethical approval) failed to attract any more participants.

Though I had hoped to recruit a further family, six interviews meet the criteria for Smith et al. (2009) who state that the novice researcher should aim for around six participants, and that doctoral research should consist of 4-10 interviews. I was initially concerned regarding the fact that there were only two families partaking, however IPA does not claim to present generalisable findings, rather it offers in depth analysis of the participants' experiences, and what it has meant for them. By having a smaller number of participants, it gave me space for a greater in-depth analysis, whereas more participants may have diluted the families' experiences.

3.4. Data collection

Participants were fully informed regarding the scope of the research prior to the interview commencing. I took the opportunity at the start of the interview to go through the consent form, and to check whether there were any questions. I also reminded participants of their right to withdraw at any time, both during the interview, and in the 14-day period following.

Due to the small number of participants, I did not carry out a pilot interview. I also felt that as I had previous experience of IPA, I was confident in the process. However, on reflection, all of my previous interviews had been conducted with adults. I feel that it would have been helpful to carry out a pilot interview with a young person, in order to gather feedback on what they thought, and whether there was anything I could do to put them more at ease. All children were offered the opportunity for pre and post interview activities, but none chose to take part in them, giving the sense that they were there with ‘a job to do.’ I spent time reflecting after each interview. One of the key reflections I had was on the difficulty in carrying out an IPA interview with children. As previously noted, one of the children spoke at great length about their experiences, however the other two children spoke in often one-word answers, or short sentences. I often found myself asking direct questions, in order to try and understand their experiences. Prompts of ‘how did you feel about that’ or ‘can you tell me some more’ often failed to elicit more detailed answers. It felt important however, to be led by the children and what their experiences and beliefs of their illness were. I reflected my concerns around this in supervision and identified that it was likely the children were used to being chronically ill and the experiences they were having in school, so were possibly reflecting on it for the first time themselves or did not understand my interest in their experiences. I also considered the possibility of rapport building, and how being someone they met only once and online, may have contributed to their reluctance to open up to me. In the future, I may opt to have a ‘meet and greet’ session with the children prior to the day of the interview. Of interest, parents were present for these two interviews (at the request of the child), and I wonder how this influenced the child’s responses, and whether they felt able to talk freely, or if they felt the need to present a certain viewpoint in the presence of their parent, as it was these two interviews where the children were more difficult to engage.

Interviews with the caregivers seemed much more ‘straight forward.’ I had devised a semi-structured schedule through supervision (Appendix H) to help guide my interview. The parents however tended to cover most, if not all of what I wanted to ask as they spoke. Interviews usually begun by asking demographic details such as the age of the child, and what school year they were in. Parents generally started by talking about the diagnostic process for the medical condition, before leading into telling school about the medical needs. I would let parents talk as they wished, before asking to return to certain points with clarifying questions. This is because I wanted to give them space to tell their ‘story’ without interruptions to their flow from me. I tried my best to remain neutral as parents spoke, however when there were particularly emotive sections, I did find myself offering words of empathy or support, which is what I believed to be an appropriate response to safeguard the participants' wellbeing.

IPA is considered to have a double hermeneutic, whereby the researcher is interpreting the participants' interpretation of their experiences (Smith et al., 2009). Caregivers did often fall into talking about the impact that the experiences had on their child, thereby presenting a triple hermeneutic. This is acknowledged in part two of the thesis. It was often difficult to steer parents away from talking about the child's experience. As noted in part two, this is interpreted to be due to the fact parents are often advocates for children and young people, and as such will often speak 'for' the child (Siegle, 2008). It may also be that parents wanted to be sure the experiences of their child were clear to me, given the difficulty of eliciting the views from the young people themselves. As noted earlier, the children often spoke less when their parents were present, and I wonder whether this might be an implication for practice – does the child's voice get lost when they do not have the opportunity to speak freely without their caregivers' present?

3.5. Data analysis

Though I settled on IPA as my analysis, I had considered the use of thematic analysis (Clarke et al., 2015), as this also fitted with my ontological and epistemological stances. This approach would have allowed me to look for patterns across the interviews, however I was concerned that I would lose the unique experiences of each participant if I used this form of analysis. I settled on IPA, as I was hoping to understand the participants' lived experiences, and how they themselves were making sense of said experiences (Smith & Shinebourne, 2012). I was not testing a specific hypothesis, but rather, 'getting curious' about what the participants said, and the similarities and differences across participants' experiences. I felt that the use of IPA would allow me to keep an ideographic focus, as well as a broader thematic focus (Braun & Clarke, 2021). Furthermore, IPA is a recommended approach if the data set includes personal experiences, such as experiences with health (Smith et al., 2009).

Analysis of the data and emerging myself in the transcript was a time consuming, and difficult aspect of the research, due to how labour intensive I found the process. However, as evidenced by Smith et al. (2009) immersion in the data, reading and rereading, and detailed note making are key steps in IPA. It was sometimes difficult to bracket my own emotions when thinking about the difficulty some of the participants had with education, however I feel I have done my utmost to ensure my own experiences and preconceptions are not evident in the analysis, through utilising supervision, a research diary, and immersing myself in the data, continuously returning to the transcripts to ensure my interpretations remained true to the interviews (Finlay, 2008). I also grappled with being interpretive with the data whilst remaining true to the participants' stories – however this is something I am proud of and feel I have achieved.

Consideration was given as to whether it would be appropriate to return to the participants to seek their views on whether they agreed with my interpretation of their experiences. However, following some reflection in supervision, I decided this would be straying too far from the ethos of Smith et al. (2009) and IPA, where the focus is on my interpretation as the researcher.

I also grappled with whether IPA was still appropriate to use for the children's interviews, given the difficulty I had experienced in eliciting their views, or whether I should be considering thematic analysis. However, I reflected on this in supervision, and decided that it was appropriate to still use IPA as the presentation of the children and their answers itself was something to be curious about, and to consider what this might mean through an interpretive phenomenological lens.

Writing up, and synthesising the level of information that I had, proved difficult. The participants had shared a significant amount of rich information with me, and I found it a challenging task to choose which illuminated the experiences best. In terms of presenting the discussion, I felt that a section under each superordinate theme was too restrictive, as often the sections flowed into each other, and there were cross overs to be seen between the experiences of the caregivers and the experiences of the children. Smith et al. (2009) do not advocate for a set way of presenting the discussion, and as such, I presented it in a way that I felt was most appropriate. Similarly, I presented the adults' experiences first, as I felt as though the information they provided gave context to the children’s experiences, which I believed would be helpful for the reader.

When presenting my considerations in the discussion, I did consider some other psychological theory that I felt might provide context and help frame the experiences of the families. Grappling with what was appropriate to include, and what should be excluded provided a level of tension and dilemmas for me, as I considered where my boundaries should lie, and how far I should push my interpretations. I particularly grappled with the inclusion/exclusion of locus of control (Lefcourt, 1991) and social defence theory (Krantz, 2010), as I felt these might provide some further contextualisation of the family’s experiences; Locus of control (Lefcourt, 1991) might help us understand why the children have accepted their conditions and the experiences that come with them, and why parents find this more difficult. Similarly, Social defence theory (Krantz, 2010) may have provided some discussion around school’s difficulty accepting the children in the context of the systemic pressures placed on them. Ultimately, I chose to exclude these theories for two reasons. The first reason being that attributing experiences or reasons to teachers/school staff when they have not been interviewed falls outside the remit of this research and is instead something to consider for future research. The second being that Smith et al (2009) argue that psychodynamic theory (such as social defence theory) lies outside the remit of IPA, and therefore I would be straying too far with my interpretations.

3.6. Ethical considerations

Ethical approval for this research was slightly more difficult than I had anticipated, and though I felt I had considered all aspects of the research, the ethics committee did send the application back with some thoughtful considerations around the use of video recording vs audio recording. Ethical considerations are included in full in appendix L.

The topic of chronic illness can be an emotive one, and particularly in the parental interview, emotions were heightened on a number of occasions. Participants were reminded at the start of the interview that they could take breaks, however on reflection, I feel that I should have explicitly asked if parents needed a break when I could sense they felt emotional. Similarly, for the children, they were offered breaks, and I made sure with Morgan in particular to check in and offer this to him during the session as this was something that had been raised during email communication with his mother.

I was conscious about the impact of the research, and ensuring the participants were not distressed following the interview. I offered a number of links in the debrief sheet (Appendix I & J) as to where participants could seek further support if they felt they needed it following the interview. I also talked with the participants about unrelated topics following the interview, to create a ‘transition’ back into the rest of the day. The children in particular were offered games at the end of the interview, but none felt they needed it, and often they wanted to head off and get on with something of their choosing. I also explained to participants that they could receive the transcripts, or full copies of the research, but none expressed interest in either.

I also reflected on the vulnerability of participating in IPA research vs other methods. It is not anonymous, it is obvious who the participants are, I know their name, their location, their schools etc. I ensured that I took extra care to remove all identifying data from the research, to ensure anonymity for participants. I also ensured I used audio recording for further anonymity, though video recording may have been helpful to give non-verbal cues.

3.7. Researcher position

As was acknowledged earlier in the research and reflective summary, I myself have a number of chronic health conditions. This piqued my interest as to the experiences of school age children with chronic health conditions, and what it might be like for them. I took efforts to bracket my own experiences of being chronically ill through the use of research diaries and supervision, however I recognise that I am bringing personal experiences that are connected to the research, and I believe that this has enriched the data, as the data has influenced my own beliefs and experiences (Finlay, 2008). I also took steps to ensure that I did not share that I have a chronic illness with any of the participants prior to the interviews as I did not wish to influence their answers. My experiences of being chronically ill in higher education were largely positive - I was however fully expecting to hear negative stories from all participants due to the literature I had read on the subject – and particularly as I considered they were most likely to be the individuals who wanted to tell their story. I was surprised when one family felt that they had had relatively positive experiences of school, and that their concerns largely focused on social needs and experiences outside of school. I was also struck by how the experience seemed to affect parents far more than the children – however I wonder if this is to do with the children often having little (or no) recall of what their life was like before the diagnosis, whilst parents were mourning for their healthy child, and what might have been (Penzo & Harvey, 2008).

I am also conscious that despite best efforts to remain neutral throughout the interviews, there are evidently incidents scattered throughout the transcript where I may have inadvertently guided participants, either through my reaction to a point they made, or through my questioning. It is difficult to remain neutral when hearing difficult stories, and I was particularly aware that as the interviews were conducted online, participants would find it harder to note my non-verbal cues and would need more explicit verbal ones to show that I was hearing their stories and that I was empathising with them. Striking the balance between building rapport and being open and friendly whilst remaining indirective was particularly difficult with the children. Due to their short answers and lack of openness, I often found myself asking direct questions, rather than just remaining curious. However, this was in keeping with the flexibility and ethical approaches of IPA and kept participant wellbeing at the forefront of my research.

4. Contribution to knowledge

4.1. Contributions of research findings to existing knowledge

This research examined both caregivers' and the chronically ill child's experience of education. Six superordinate themes were identified through the caregiver's interviews, and five were identified through the interviews with the young people. Some of the findings were unique to the each group, however there were also some superordinate themes that were applicable to both the young people and the caregivers.

I feel that I have also offered a unique lens on the experiences of chronically ill children and their caregivers. I feel that my framing of the findings using Maslow's hierarchy of needs and the grief cycle offer new perspectives that, to my knowledge, are not already offered. I believe that this framing may also support practitioners when they explore the experiences of children with chronic illnesses and their caregivers and may offer a new approach to support for these families.

Much of the findings reflected what was already identified in the research, as outlined in the discussion section of part two of this thesis. What I hope I have offered as a unique contribution is outlined above. Similarly - to the best of my knowledge – this is the first use of IPA to explore the experiences of chronically ill children and their caregivers, specifically in relation to education. I have attempted to immerse myself in the experiences of participants and interpret their experiences, rather than describe them. The semi-structured interview approach has allowed participants to talk to what is most important to them, rather than having me impose strict parameters over the information they could share. This (hopefully) meant that the research shares what is most important to the participants. This research is (again to the best of my knowledge) the only UK based research that looks at the broad experiences of chronically ill children and their caregivers, rather than a specific condition, or only seeking the views of one or the other.

I hope that this research highlights that, despite not having a diagnosable learning need, children with chronic illnesses (and by extension, their families) still often require structured intervention and support in school to reach their full potential. I hope this research will go some way to helping school staff, and other professions, consider their constructions on how able they perceive chronically ill children to be, and how they should support them when they are attending school.

Whilst this research is based on the experience of two families it does draw parallels with previous research – and therefore evidences some theoretical generalisability (Smith et al., 2009). I hope it may provide a starting point for conversations in schools regarding the needs of chronically ill children.

Despite this, I have some concerns that this research will not be used to promote the change these children need and deserve. Previous research has also highlighted the need for understanding of the children, as well as strong relationships and adaptations, and yet, as evident from my research, these concerns are often still ongoing. As noted throughout part two, there are systemic tensions evident which may create barriers to change. Similarly, teacher confidence and understanding, and the class sizes for which they are responsible may also create some barriers to change. I acknowledge I do not have the answers for all the difficulties in implementing change, but instead provide some initial thoughts of my own as to the barriers and difficulties.

4.2. Contributions to future research

This research looked at the experiences of chronically ill children and their caregivers. It provided interesting perspectives, and of note is the difference in experiences between caregivers and the children of the same phenomenon. It might be interesting in the future to conduct exploratory research where the child and the caregiver are jointly interviewed, with a focus on a specific event e.g. the return to school. Careful consideration will need to be given to management of such research, to ensure the young person is not ‘talked over’ as research suggests that parents might continue to seek the need to advocate for their children, even during a research interview, due to previous experiences of needing to fight for their child (Rafferty & Sullivan, 2017).

It may also be interesting for research that takes a holistic view, and interviews young people, caregivers, and staff. Some previous research has interviewed the adults around the child, but it would be of interest to take this further and gain more perspectives – this would also be in line with how EPs tend to work, seeking the views of all those involved. It is also of note that only one father joined the interviews, likely reflecting the fact that mothers are usually the main caregiver (Price, 2006) – the lack of male participation is this research may raise questions regarding societal expectations for the role of the caregiver (McKie et al., 2001). This is in line with previous research. Further research may wish to explicitly focus on father views. Though this research followed the suggestion of using IPA to explore different viewpoints (Smith et al., 2009), I suspect it could be taken further in the ways noted above.

Academic attainment was noted by caregivers in this interview and is also referenced in previous research. The majority of this has relied on parental or child self-report. It would be interesting to have an accurate measure of the child's ability to contrast with their current attainment in school. This may allow us to explore Hilliard et al. (2015) claims of chronically ill children having the potential to either perform in line with, or outperform their healthy peers.

As noted above, there also seem to be a number of barriers to change being affected. Further research to understand these barriers, and suggestions of potential ways to overcome them may be pertinent.

4.3. Dissemination

A natural next step of this research would be dissemination through publication, though consideration may need to be given as to how best to do this; whilst condensing the paper in its current state, or through two separate papers, one evidencing the caregiver experience, and the other that of the child. My preference would be to keep the paper as one, as I feel the experiences are best considered together. I strongly believe these findings are relevant to the role of the EP, but also the role of school staff, and other professionals who may come into contact with the child. The experiences of chronically ill children stretch across many domains, and I believe that this research does not need to be restricted to the field of education, or educational psychology, but can encompass wider areas such as medical journals.

The main finding from this research, is that understanding from school staff, and strong relationships between parents and school are key to providing an environment that is conducive with chronically ill children reaching their potential and reducing stress on parents. Training on chronically ill children and supporting their needs might be pertinent in the light of this. I am conscious that there are a wide number of chronic illnesses, all different from each other, as well as the fact that children will experience things differently depending on several factors. Training may wish to take a broader approach, looking at the emotional, social, and educational impact and how to address these, rather than condition specific approaches. Schools may also be actively encouraged to seek out specific training, often offered by charities, pertaining to the medical needs of the children they work with.

4.4. Relevance to Educational Psychologists' practice

This research feels very timely, with the implementation of ALNET (Welsh Government, 2018). The Act expands its definition of disability to encompass those with ongoing medical conditions. It also signifies a closer working relationship with the health service. As such, this research raises the need for EPs to be aware of chronic health conditions.

It also raises the importance of the collaborative approach that EPs take to meeting the needs of the child, as well as underlining the importance of taking time to seek out, and unpick the different constructions that individuals have. This research has highlighted how important it is to work with parents to gain a better understanding of the needs of the young person – they are often experts in the child and can relay information that can help us formulate. It was noted in this research however, that schools perhaps do not see the value in, or do not understand the importance of working collaboratively with parents. Often parents felt dismissed, or that staff felt that they 'knew best' in regard to the child. These misunderstandings further highlight how the EPs role of mediation, and reflection, reframing and reconstructing is vitally important to promoting change for these young people.

On a personal level, this research has allowed me to expand on my understanding of chronic illnesses, beyond the bounds of my own experiences. It has allowed me to develop my knowledge of the impact of being diagnosed as a child and navigating an already complex period of life. I feel confident that I would now be able to explore the needs of a family who are experiencing difficulties specifically relating to the child having a chronic illness. Similarly, as an EP, I avoid placing myself in the expert role of the child, instead taking on the role as a knowledgeable other in terms of the skills in psychology and consultation that I have. This deepened understanding of the needs of chronically ill children will allow me to perhaps offer training to school staff, to upskill those who work closest with the child or may help me to offer alternative perspectives during consultation with school staff.

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Appendices

Appendix A – Search terms used for literature review

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Appendix O – Validity of qualitative research

Appendix P – Example of transcript for Sarah (Emily's interview) with exploratory comments and emerging themes

Appendix Q – Example of transcript for Joe, with exploratory comments and emerging themes

Appendix R – Superordinate and subordinate themes for all participants with emerging themes noted

Appendix S – Excerpts from research diary – reflections on interviews

Appendix T – excerpts from research diary – recruitment strategy.

Due to their size, the completed transcripts have been submitted separately.

Appendix A – Search terms used for literature review

Database	Search terms	Number of results
Education Resources Information Centre (ERIC)	“chronic illness” or “Chronic Condition” or “long term illness” or “Long term condition” or “continuous Illness” or “Continuous condition” AND child* or Teenager* or adolescence or “young person” AND parent* or care* or guardian or mother or father or mum or dad or mam AND experience* or understand* or opinion* or view* AND school* or education* or learn*	262
PsychInfo	“chronic illness” or “Chronic Condition” or “long term illness” or “Long term condition” or “continuous Illness” or “Continuous condition” AND child* or Teenager* or adolescence or “young person” AND parent* or care* or guardian or mother or father or mum or dad or mam AND experience or understand* or opinion* or view* AND school* or education* or learn*	422
British Education Index (BEI)	“chronic* ill*” or “Chronic* Condition” or “long term ill*” or “Long term condition” AND child* or Teenager* or adolescen* or youth or student AND parent* or care* or guardian or mother or father or mum or dad or mam AND experience or opinion* or view* AND school* or education* or learn*	2
Medline	“chronic* ill*” or “Chronic* Condition” or “long term ill*” or “Long term condition” AND child* or Teenager* or adolescen* or youth or student AND parent* or care* or guardian or mother or father or mum or dad or mam AND experience or opinion* or view* AND school* or education* or learn*	748
Scopus	(TITLE-ABS-KEY (education OR school) AND TITLE-ABS-KEY ("long term illness" OR "chronic illness") AND TITLE-ABS-KEY (experience OR perspective OR opinion*) AND TITLE-ABS-KEY (parent OR caregiver OR mother OR father OR guardian) AND TITLE-ABS-KEY (children OR adolescent OR teenager OR "young person"))	207
Applied Social Sciences Index and Avstracts (ASSIA)	noft(education OR school) AND noft("long term illness" OR "chronic illness" OR disability) AND noft(experience OR perspective OR opinion*) AND noft (parent OR caregiver OR guardian OR mother OR father) AND noft (Adolescent OR Teenager OR Young Person OR child*)	270

Appendix B – gatekeeper letter

School of Psychology
Ysgol Seicoleg

Permission to recruit participants

Dear [name of contact]

My name is Rachel and I am a doctoral student in the School of Psychology, Cardiff University. As part of my degree, I am carrying out a study on the experiences of both chronically ill children and their caregivers' experiences of education. I am writing to enquire whether you would be willing to support my recruitment of participants in this research.

As part of this research, I will be interviewing children and their caregivers separately about their experiences. Both interviews will be conducted via Zoom, and is expected to take no more than 60 minutes each. The interviews will be audio recorded, transcribed, anonymised and then subsequently deleted. Ethical approval has been given by the school of psychology, and I am under the supervision of Dale Bartle, a tutor on the Doctorate of Educational Psychology.

If you are happy to allow me to recruit through your charity/Facebook group I would be incredibly grateful. I have attached a flyer containing information about the project, and well as further information sheets for your circulation.

Many thanks in advance for your consideration of this project.   Please let me know if you require further information. You can also get in touch with Dale, or the ethics committee for further information.

Regards
Rachel Jones

Rachel Jones	Dr Dale Bartle
Trainee Educational Psychologist	Co-Director / Research supervisor
Jonesrl15@cardiff.ac.uk	BartleD@cardiff.ac.uk

Ethics Committee – Psychethics@cardiff.ac.uk or 02920 870360. You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Privacy Notice:

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Rachel Jones.

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 2 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only Rachel Jones (the researcher) will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix C – Recruitment poster

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

School of Psychology
Ysgol Seicoleg

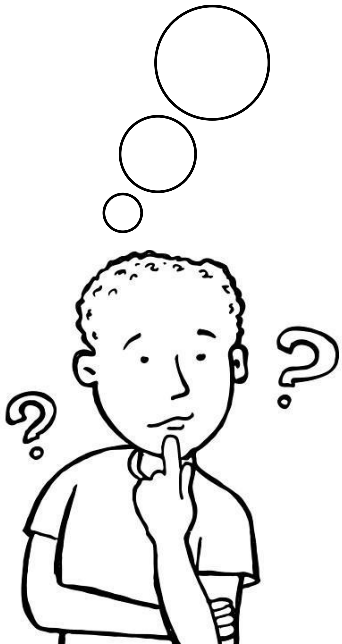
Are you the caregiver of a chronically ill child?

My name is Rachel, and I am a doctoral student at Cardiff University. I am looking to speak to caregivers and their child about their experiences of education whilst chronically ill. I would like to better understand how educational psychologists can support both the child and their family.

If your child is:

- 11 -16 years old
- Has a chronic illness
- Has an attendance of 90% or below as a result of this illness, &
- Has no other educational needs

Then please get in touch.



For more information, or to express an interest, please email Rachel at jonesrl15@cardiff.ac.uk

Supervised by Dale Bartle – Bartled@cardiff.ac.uk.
Full ethical approval given. For queries or concerns, please contact the researcher in the first instance. You can contact the Ethics committee on Psychethics@cardiff.ac.uk or 02920 870360. You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Appendix D – Caregiver information sheet

Chronically ill children and their caregiver's experiences of education

Information sheet

Introduction

My name is Rachel, and I am currently a second year Trainee Educational Psychologist at Cardiff University. This study is my thesis research and is being completed as part of the requirement for completion of the course. This research is concerned the experiences of chronically ill children and their caregivers, in particular, their experiences of education. I would like to invite you, as a family who have a child with a chronic illness, to participate in this research. Before you decide to take part in this study, it is important for you to understand why the research is being done, and what it will involve. Please read the following information carefully.

Purpose of the study

The purpose of this study is to better understand the experiences of education for a young person who is chronically ill. It is hoped that this research will provide helpful information regarding the needs of these children and their families and will inform the work that Educational Psychologists can do to support these children and their families.

Am I eligible to partake?

You are eligible to partake if you have a child aged 11-16 who meets the following criteria:

1. They have a chronic illness. A chronic illness is defined as an ongoing medical need that is expected to need medical follow ups for over 12 months. A medical follow up is defined as repeated hospital admittance, specialist follow up as an outpatient or use of other specialist services.
2. They have persistent absences from school because of this chronic illness. A persistent absence would mean your child has an attendance percentage of 90% or below.
3. There are no other diagnosis' that might affect your/your child's perceptions of education. I.E Dyslexia, ASD, ADHD.

If you would like further information on eligibility, you can email the researcher on the email found at the end of this information sheet.

What will you have to do if you agree to take part?

1. You will need to express an interest in partaking in the research to the researcher.
2. Both the young person and their caregiver will need to read and fill out the consent form that is attached to this email.
3. At a date and time that suits you, you will need to partake in an online interview (via Zoom) that will last for around 60 minutes. This will consist of two separate interviews – one for the young person and one for the caregiver.

What are the possible benefits of taking part?

You may find the research interesting, and it will give you the opportunity to discuss your personal views and experiences. Once the research is complete, it is hoped it will provide valuable information regarding the educational needs of chronically ill children, and that this in turn may inform the practice of Local Authorities.

Will my taking part in this research be confidential?

If you agree to take part in the research, your interview will be audio recorded. Once the interview has been transcribed, it will be anonymised, and the original recording will be destroyed. Your comments will be used for the purpose of this project only, and the data will not be used in any subsequent research.

It is also important you are aware that whilst the interview is intended to be confidential, the researcher has a duty of care. If any safeguarding concerns are raised or disclosed by either yourself or your child during the session, she will be required to seek guidance from the university safeguarding officer and/or pass this information on to the appropriate professionals. If you child becomes distressed during their interview, you will be informed, as their safety and wellbeing is the researcher's priority.

What happens if I do take part?

If you are happy to take part in the research, you will individually need to complete the consent form to say you have fully understood the purpose of the research and what is involved. As the caregiver, you will need to give consent for both yourself and the young person to partake. The young person will need to also give consent to partake in their own interview. You will need to email the completed consent form to the researcher, who will then confirm a day and time for the interview to take place. You are free to withdraw from the research at any time, in the first 14 days following the interview. You will be interviewed individually, and your child will be given the option as to whether they would like to interview alone, or to have you present in the room. Both you and your child will have the option to take breaks, or to complete the interview over more than one session if you prefer. You and/or your child are also able to see the interview questions in advance if this would be helpful.

Who can I contact if I have concerns about the research project?

If you have any concerns, please contact the research in the first instance to see if this can be resolved. If you have any further queries or complaints, you can contact the research supervisor or the ethics committee at Cardiff University. These details can be found below:

Rachel Jones (Researcher) – Jonesrl15@cardiff.ac.uk

Dale Bartle (Research Supervisor) – bartled@cardiff.ac.uk

Ethics Committee - psychethics@cardiff.ac.uk or 02920 870360
Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

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The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 2 years.
The research information you provide will be used for the purposes of research only and will be stored securely. Only Rachel Jones (the researcher) will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

School of Psychology
Ysgol Seicoleg

Appendix E – Young person Information sheet

This is me!

My name is Rachel, and I’m studying a doctorate at Cardiff University. I’m doing this to train as an Educational Psychologist. You may not have heard of that job before, but what it means is that I work with young people to find out what they like, what they find difficult and how I can work with the adults around them to try and help make things a bit better for them.

As part of my course, I must do some research. What I have chosen to find out more about is children who have chronic illnesses. I’d really like to know more about your experiences of going to school whilst chronically ill. I’ll also speak to your caregiver too, to see if there is anything they might be able to tell me. I’d like to speak to you so I can find out about your experiences, and see if there is anything else that the adults could do to help other children like you in the future.

If you want to talk to me, we will have a chat online via video. I have some questions I will ask you and I will be recording the audio, so that I can type up what we have said after the call. It is up to you what you share with me when we talk, but it is important that you know that if you share something that makes me worry about your/someone’s safety, I may need to tell your caregivers, or another professional who can help. We can also take breaks, or complete the interview over more than one session and you can also stop the interview at any time if you don’t want to carry on talking to me. If there is something you have told me that you want me to not include, or you change your mind, you will have two weeks (14 days) to let me know. After this point, I will have anonymised the chat – this means I’ll have written it up and deleted your name (and the audio) so I won’t be able to tell which chat is yours.

If you are happy to talk to me, please let your caregiver know. They will get you to sign a consent form (which means you understand what we are going to talk about) and then they will arrange a time and date for us to talk. If you are feeling a little nervous to talk to me, then we can play some get to know you games before we start. If you feel a little sad after talking to me, we can play some games to cheer you up too. You can choose to talk to me alone, or to have your caregiver in the room with you. You can also see the questions I’m going to ask you before you agree to take part if you would like. It will all be your choice

If you have any more questions, you can email me (Rachel) at jonesrl15@cardiff.ac.uk – If you are not happy with my answers, you can email my supervisor Dale on bartled@cardiff.ac.uk or the ethics committee (the people who decide if it’s okay for me to carry out my research) on psychethics@Cardiff.ac.uk or 02920 870360. You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Thank you

Appendix F – Caregiver Consent form

Children and their caregiver's experiences of education with a chronic illness

Consent Form

1. I understand that my participation in this research will involve both myself and my child completing an interview via Zoom, which will be audio recorded, transcribed, and then deleted.
2. I understand that participating in this research will take approximately 60 minutes per interview.
3. I understand that my child and I's participation in this study is entirely voluntary and that I can withdraw at any time during the interview, and in the 14-day period following the completion of the interview.
4. I understand that following the 14-day period my data will have been anonymised, at which point I will be unable to withdraw.
5. I understand that I am free to ask questions at any time. I am free to withdraw from the study prior to the point of anonymisation or discuss my concerns with Rachel Jones (Researcher), Dale Bartle (Research Supervisor) or with the ethics committee at Cardiff University.
6. I understand that the researcher has a duty of care to my child, and that she will pass on any concerns to me or to the safeguarding officer/other professionals as appropriate.
7. I understand that at the end of the study I will be provided with additional information and feedback regarding the purpose of the study.
8. I understand that following the point of anonymisation, all data held will be completely anonymised and it will be impossible to trace the data back to me individually.
9. I understand that this research will be shared with Cardiff University as part of the requirement of the Doctorate in Educational Psychology course.
10. I understand that the anonymised data may be retained indefinitely and/or published as part of a wider dissemination of the research.

I consent / do not consent to partake in this research into chronically ill children and their caregiver's experiences of education (please delete as appropriate).

I consent / do not consent to my child ________________ partaking in this research into chronically ill children and their caregiver's experiences of education

Signature: Date:

Please return the completed consent form to Rachel Jones via jonesrl15@cardiff.ac.uk

Thank you.

If you have any questions or queries, please contact the researcher in the first instance. You can also contact Dale (Rachel's Supervisor) – BartleD@cardiff.ac.uk or the Ethics Committee - psychethics@cardiff.ac.uk or 02920 870360. You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

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The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 2 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only Rachel Jones (the researcher) will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix G – Young person consent form

Children and their caregiver's experiences of education with a chronic illness

Consent Form

1. I understand that I will have a chat with Rachel (the researcher) via Zoom, which will be audio recorded.
2. I understand that this chat will last for about 60 minutes and that Rachel will be asking about my experiences of having a chronic illness and going to school.
3. I understand that talking to Rachel is entirely my choice and that I can ask to stop at any time during the chat.
4. I understand that Rachel will type up what I say and use it to write a research report about my experiences of going to school with a chronic illness. For 14-days after we have spoken, I can ask Rachel not to include what I have said, after that, she will have typed up the chat, and deleted the recording. Rachel will not be able to tell which chat is mine after this point.
5. I understand that if I have any questions or worries, I can email Rachel, her supervisor Dale, or the ethics committee (the people who decide if Rachel can carry out the research).
6. I understand Rachel will not use my name in this research report, so nobody should know it is me who has said these things.
7. I understand that Rachel will share her report with others, so they can see what she has found out.
8. I understand that if I get upset, that Rachel will need to tell my caregiver.
9. I understand that if I tell Rachel something that means I am unsafe, Rachel will let my caregiver, or a professional know to help keep me safe.

I will / Will not talk to Rachel about my experiences of having a chronic illness and going to school (Please cross out as appropriate)

Signature: Date:

Please return the completed consent form to Rachel Jones via jonesrl15@cardiff.ac.uk

If you have any questions or queries, please contact Rachel first. You can also contact Dale (Rachel's Supervisor) – BartleD@cardiff.ac.uk or the Ethics Committee - psychethics@cardiff.ac.uk or 02920 870360. You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Thank you.

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The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 2 years.
The research information you provide will be used for the purposes of research only and will be stored securely. Only Rachel Jones (the researcher) will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix H – Semi-structured interview schedule

Questions for children

1. Can you tell me about your illness?
2. Can you tell me about your experiences of education/school? (prompts in terms of when condition is managed vs not managed)
3. What have school done that is helpful?
4. What have school done that is not so helpful?
5. How do you think other people see you?
6. How do you see the future for yourself?

Questions for caregivers

1. Can you tell me about your child’s illness?
2. Can you tell me about your experiences of education for your child?
3. What have school done that is helpful?
4. What have school done that’s not so helpful?
5. How do you think other people see them?
6. How do you see the future for them?

This is not a strict schedule, and the interview will be guided by the participants.

Optional pre/post interview games to play with the young people

Pre-interview icebreaker - https://rollthedice.online/en/cdice/get-to-know-you-die

Post-interview – using the whiteboard option to play Pictionary or hangman.

Appendix I – caregiver debrief form

Chronically ill children and their caregiver's experiences of education

Debrief Form

This study is a thesis research project being completed as per the requirements of the doctorate in Educational Psychology course. This research is concerned with Chronically ill children and their caregivers experiences of the education system.

The purpose of this study is to investigate and better understand the experiences of chronically ill children and their caregivers with regards to education. It is hoped that this research will provide insight into how the experience of education has been for both children and caregivers, and will hopefully provide guidance as to how Educational Psychologists can support these families in the future.

Once this research is completed, it will be given to Cardiff University as part of the requirement of the Doctorate in Educational Psychology. Should you wish to see the final report, please contact Rachel Jones on the email below.

If you have any further questions, queries or comments regarding the research, please contact Rachel Jones in the first instance. If you are unsatisfied with your response, you may contact Dale Bartle, Research Supervisor or the ethics committee for further information.

If you would like further support following this interview, you may wish to contact your GP or your child's school to explore the options available to you. Alternatively, you can contact MIND on 0300 123 3393 9am-6pm Monday to Friday, for signposting and support. Outside of these hours, The Samaritans are available on 116 123. You may also wish to partake in some self-care activities that you enjoy, such as watching a film, listening to music, going for a walk or taking a bath.

Thank you for participating in this research.

Rachel Jones (Researcher) – Jonesrl15@cardiff.ac.uk

Dale Bartle (Research Supervisor) – BartleD@cardiff.ac.uk

Ethics Committee - psychethics@cardiff.ac.uk or 02920 870360.You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

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The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 2 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only Rachel Jones (the researcher) will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix J – Children’s debrief form

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Chronically ill children and their caregiver’s experiences of education

Debrief Form

This research is being completed as part of my course, a Doctorate in Educational Psychology. I wanted to find out more about the experiences that you, and the people who care for you, have had of school. I wanted to understand if you were having good or bad experiences, and to see if I could try and understand your needs. I am hoping that my report will mean that Educational Psychologists and other professionals will have a better understanding of how we can support you and your family in the future.

Once this research is completed, it will be given to Cardiff University. If you would like to read what I found out, you can let me know by emailing me.

If you have any further questions or please give me an email. If you are not happy with my response, you may contact Dale Bartle, my Supervisor, or you can email the ethics committee below too.

If you are feeling sad after our conversation today, you might want to talk to an adult you trust about how you are feeling. If you don’t feel able to do that, you can also talk to Childline. You can call them on 0800 11 11 or talk to them via their website www.childline.org.uk. The Childline website also has some good self-care activities that may help you feel better. You may also want to do something you enjoy, like drawing, playing a game or spending some time outdoors.

Thank you so much for taking the time to talk to me about your experiences!

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Dale Bartle (Research Supervisor) – BartleD@cardiff.ac.uk

Ethics Committee – Psychethics@cardiff.ac.uk or 02920 870360.
You can also write to them at Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Privacy Notice:
The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Rachel Jones.
The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 2 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only Rachel Jones (the researcher) will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix K – Data analysis procedure (Interpretive Phenomenological Analysis)

The following analysis procedure was used, as suggested for novice researchers by Smith, Flowers and Larkin (2009).

Transcription

The researcher used automatic transcription software for the initial transcription of the interviews. The researcher then went through each transcription line by line, checking for accuracy, and adding in pauses, gestures and any other information not accounted for. The researcher then listened to the recording a second time whilst reading the transcript to allow for full emersion.

Reading and re-reading

The researcher read and reread the transcript several times.

Initial noting

While reading and re-reading the transcript, the researcher made annotations reflecting her thoughts and feelings. These notes were made using codes to identify whether they belonged to language, concepts, or description.

Developing emergent themes

Once the researcher was satisfied, she had deconstructed the transcript, she began to note emerging themes.

Searching for connections

The researcher then began to sort and assimilate emerging themes to identify groupings.

Moving on the next case

The researcher then repeated steps 1-6 with the remaining transcripts. Further emergent themes were collected and added to previous subordinate/superordinate themes when and if appropriate to do so.

Looking for patterns across cases

Once all transcripts had been analysed, the researcher attempted to discover patterns and contrasts across the six cases. The research chose to look for connections between the three adult interviews and identify themes here, before repeating the process with the children’s interviews. The researcher made every effort to recognise the individuality of each individual, whilst looking for commonalities.

Appendix L – Ethical considerations

Concise statement of the ethical considerations and how these will be managed

1. Researcher access/exit – Informed consent will be sought from all those participating. Participants will have the opportunity to ask questions both prior to and following the interview. The researcher will make every attempt to ensure that they are leaving the participant in the same emotional state as prior to the interview.
2. Power and participant relationships – Participants will be reminded that this is not a usual adult/child interaction, and that they are free to tell the researcher as much/as little as they would like, and that they can stop the interview at any time. This will be made clear at the start of, and during the interview. Participants will also be reminded they can change their mind in the period of time following the interview, but before anonymisation. Consideration towards power and participant relationships will also be given during the write up.
3. Information given to participants – Participants will be given the true purpose and task requirements. Participants will receive full information before consenting to partake.
4. Participants right to withdraw – Participants will be able to withdraw at any point during the interview. Following the interview, they will have 14-days in which to contact the researcher to request to withdraw. Following this, their interview will have been anonymised, and therefore withdrawal will not be possible.
5. Informed consent – This will be obtained via the consent form sent in advance of the interview, a signed copy of which will be returned to the researcher. The researcher will confirm the participant has read through the form and is happy to consent at the start of the recording.
6. Complaints procedure – Contact information for the researcher and their supervisor will be on both the information and the debrief forms. In the first instance participants can contact the researcher, and in the unlikely event they are unsatisfied, they will be directed to the research supervisor for further information. They will also be provided with the contact details for the ethics committee at Cardiff University, should they wish to escalate their complaint.
7. Safety and well-being of participants –Due consideration will be given to the participants wellbeing. Whilst the researcher does not intend to deliberately induce

anxiety/distress, they recognise that this may be an emotive topic.

Prior to the interview - Participants will be able to see the interview questions in advance, and will be aware of the intent of the interview throughout, there is no deception. The young people will have the opportunity to play icebreakers with the researcher to help them feel more comfortable.

During the interview - Participants will have the right to stop the interview at any point during it – the researcher will also pause the interview if the participant appears distressed. The participant will have the opportunity to take a break before recommencing, recommence the interview at a later point, or withdraw from the research completely. Furthermore, they will have the opportunity to withdraw from the research up to the point of anonymisation.

After the interview - Once the recording of the interview has finished, the researcher will then spend some time with the participants, checking on their wellbeing. The children will be offered the opportunity to partake in some games and light-hearted activities both prior to beginning the interview and before terminating the call (Appendix H), and the researcher will also encourage all participants to conduct some self-care activities following the interview. The researcher will work with the participant to identify self-care activities of their choice during the call, and there are also some suggestions on the debrief forms for both adults and young people (Appendix I & J) The researcher will be available via email following the interview, and will also provide contacts and/or suggestions for alternative support (i.e. charities, GP, school). As the researcher is a trainee Educational Psychologist, and a trained Childline counsellor, she has good therapeutic skills, including (but not limited to) active listening, reflection and empathetic approaches. These skills will be utilised throughout the interviews, and following the interview to support both the caregiver and the young person.

Safeguarding - The researcher will make the children aware they may contact their caregiver (if they are not present during the interview) if they have concerns regarding their wellbeing following the interview. Both the caregiver and young person will be made aware that the researcher has a duty of care, and if there are any disclosures, the researcher will need to contact the caregiver, and/or professionals if need be. The researcher will contact her supervisor (Dale Bartle) and/or the safeguarding officer for the School of Psychology (Katherine Shelton) if she has non-immediate concerns regarding the young person and/or their caregiver. If she has immediate concerns, she will contact 101 (Welsh Government, 2021) or the Local Area Safeguarding board.

8. Anonymity/confidentiality – All data collected will be transcribed and anonymised within a 14-day period, at which point the original recording will be destroyed. Participants will be unable to withdraw following this point. Informed consent will be kept separately from the transcriptions.
9. Data collection – Interviews will be conducted via zoom and audio recorded.
10. Data storage – All initial recordings and transcriptions will be kept in a secure encrypted folder on a password protected laptop. Once the transcription and anonymisation of data is completed, all identifiable recordings will be deleted. Informed consent forms will be kept in a separate secure folder.
11. Debrief – Participants will receive a full and accurate debrief at the end of the interview, with the opportunity to ask questions. They will be provided with contact information for the researcher, the research supervisor and the ethics committee should they have further questions or feedback. They will also be given contact details for appropriate charities should they feel the need to receive further support following the interview. The researcher will spend some time with the participants following the conclusion of the interview, to support the participants should they feel distressed following the interview. The researcher will help the participants to consider what activities they could do following the interview, to ensure they are providing themselves with self-care. A number of suggestions will also be included on the debrief form. The child participants will also have the option of playing some games with the researcher before terminating the call if this is something they would like.
12. General Data Protection Regulations (GDPR) - This project will ensure compliance with GDPR, therefore research participants will be informed as to what personal data is collected, how it will be stored, and at what point it will be deleted. They will also be informed as to how their information will be protected.

Appendix M – All quotes organised by themes (parents)

Sub theme	Parent	Line number	Quotes
Collaborating with School			
Relationships with staff	Sarah (Joe's interview)	121-124	Um, and I felt like they weren't quite listening to us because they, the teacher it happened that the teacher that had him. Her son was [condition] [ah okay] So I think really felt she knew what she was on about, and, yeah, we were quite worried about it, because we knew that [CONDITION] and [condition] don't work well together
		147-152	They put a complaint in about our [condition] nurse which was horrible. She, She got so stressed, we actually got given another [condition] nurse to help deal with it. We had to get [condition charity] involved, and it was about, about this point that I email, I wrote uh, a letter to the governors, and I gave in to the office to the governors and the same days I gave that letter in, I got a complete U turn from the headmaster who just turned around and said, Yeah, he can use his needles.
		187-190	This is where I put a complaint in, so I, I went to the governor's, then I went to the [academy] trust but because he'd been left high, I wasn't, I wasn't happy about it, but I'd started the complaint process but the next day, we had to decide whether we still sending him to school or not, because it was quite a severe thing to have happened. Obviously I was really unhappy, and the school knew I was unhappy, so it's tension anyway.
		277-284	And they, again, they, they treated us like we just weren't making the effort we weren't telling him to do it, he wasn't putting the effort in. And that's not who he is, he's really, really good at [trails off]. And he loves to get good grades and, and he was giving the best he could give, and that I found really frustrating that there was that, Miss, they would not see that it's not his fault, you know, he's doing the best he can. They would, like treat him like every other child, like well, this is the standard and it's like yeah but he's not the same, like that. Um, I think [Child] got really, really, really depressed, in that school, I think a lot of it was, partly because the pressure on him was too high. Their expectation was, they just wouldn't accept that he was slightly different
		300-303	They, they've got a couple of members of staff who do their medical stuff, and they seem to spend quite a bit of time just getting to know [child] and so if he was out of character, they seem to pick up on it a lot quicker. It's just been, the communication home was better

		307-311	but even working from home. Um, yeah, the, the, we used to get phone calls, a check in phone call, just to make sure that he was keeping up with the work that he was doing all right because obviously they weren't getting the same attendance register so they just want to make sure that, although they knew we'd be doing it, that he was okay in himself and uh, they talked to him. Find out how he felt, that, that was really good
		372-376	Um, and it's given me some consistency because it's that same person contacted me each time. So I know that they know [Child] like sometimes she phone up and say [Child] is just not quite himself and I'm not sure if I should be worried, you know, and that, that sort of stuffs been really helpful for me, because I know I've been able to say to her 'oh yeah. he didn't sleep last night' or this or that. But um, yeah, the communication, that side of it's been better.
		401-406	Um, I think, I think if school's talked to us parents more, that would be helpful, you know like when you meet - I quite often get to meet like, the head or the pastoral assistant but actually it'd be good to meet the people who are actually doing the medical care, or the. you know the people that are actually going to do it because they're the ones who you wanna meet because, yeah, that would be helpful, from my perspective, then they're not getting it second hand all the time.
		596-599	And I think that is the big difference and I think I, I, I my concern would be that senior school might be a bit more like the process, because they process, they seem to process them a bit more, in general, because they, that's them readying them for adulthood. Whereas I think you can still ready, a child and still treat them with compassion, I think that's quite important.
	Sarah (Emily's interview)	194-204	She was really, really, really nervous about going, so I spoke to them at length beforehand about all the problems we've had with attendance and um, making friends and um, one of them suggested we try and go on the parent support group for the school, and introduce ourselves and see if anyone wants to meet in the holidays, which we did and we met a few parents beforehand with little children that came around to play with her so she knew some people before she went in and I think that was really good advice. That really helped. And they said that if she was at home they would make sure that work came home, and that it was linked to what's happening in class, so we kind of headed off a lot of the problems we've had before, before we started,[pause. mmm] and it's gone really really well with that school
		409-412	I've always found that really difficult because sometimes when teachers talk to you they always talk to you as if you've got no understanding of how school and education work.

		574-580	So when [child] started they'd already got this sort of conception of who we were as a family and then [name] her older brother had medical needs as well and his problems. I kind of feel like I got tarred with this is that awkward parent, [laughs] you know, she's going to be difficult and I hate that because it's far from what I am you know I just want, I want to [cuts out] and get on with them I want to have good relationships [cuts out]
		587-592	I'm really consciously aware of how I talk to schools and what I say, and i'm really worried about how I come across. It's, uh, it makes it very difficult to ask for help, because you don't want to come across. Get them. Get on the wrong side of them because once the school, get an idea in their head of who you are, getting help becomes insanely difficult
		613-620	So, in the previous school because things got so bad with their communication with me. Um, because I was so unwell we had help from children's services they got there, um, what did they call them, um an early intervention team from the Children's Centre, [yeah] come out, and she worked with us, um, going into school got a team around the family, um, so that they would so that they couldn't back out of what they'd said, you know, on that they had to do it by a certain date and that made a really big difference.
		667-674	And in the previous school, the primary school that we were in the head teacher actually said to me, if you really, you know, if you, yeah I said something like, oh I can't remember what I said to him I said something like, Oh, it feels like you're bullying them for being different and he said, If you don't like it, Find another school, I was just like, that's, that's not the attitude to have you're not thinking about the child at all [yeah] just. Yeah, they were more worried about their figures and how it looked to, you know, than they were about the kids and their individual needs, it was horrible.
	Sophie & Ian	264-267	I think we were very lucky to be honest because of A). We had... he had his head of year... who fully understood, [Condition] because of his thingy, uh, because of his, his, his best friend having [condition] [yeah] and that helped cos he fought a lot of the battles, you know, [child] didn't have to go and try and fight with every teacher explain condition because this teacher just went 'look this is how' (mum)
Staff Knowledge and perceptions	Sarah (Joe's interview)	63-65	Yeah. So, [child] started in a primary school system, bit like [other child] did, he started, [School Name], and in reception, we, we went in before he started to explain what [CONDITION] was, most teachers had never heard of it
		82-85	Umm, the hospital gave out SOS powder, which is like pure carbohydrate and he put it into a drink for when he was having a crisis, but again, it tastes vile so trying to get him take anything was a nightmare. Um, and schools had problem with um, making it up. They used to get, like, flustered about how to do it

		117-121	We started to have a few issues, like, that was when he got diagnosed with the [condition], and it all went a bit wrong then because school were fine with the [CONDITION] they seem to understand that, they'd had - the problem was, They'd had children in before who'd had [condition], and they just assumed [child] would be like them, you know, they're like, 'oh we know about [condition].' And when we went in to do the training they're like, 'Yeah, we know we've done this before.'
		295-300	, he was there a couple of months but, um, he went in, they, they sort of got quite, they got to grips with what was wrong with him quite quickly… but um, they've been really good at understanding his uniqueness, and also they've, they've been really good at getting to know him
		389-392	They've been less afraid, to push him and see what he can do. So they, they've um, made him do the running race, you know, in the sports day and stuff, and he likes to be included and give it a go, you know, so that was nice that they let him do that sort of thing because before it's always been that 'don't wanna push him too far physically', that's, it's good to let him test where he can get to
		539-547	And I don't think they see it, they know they've got the medical needs, but they don't really think about how that affects the child, you know, if someone's feeling sick you send them home. If someone's got [condition] and they've had a Hypo and they're now treated and back in the class, they don't treat them differently, they don't think like, this child's probably feeling rubbish now, even though the imminent hypo's over, they're still left feeling shaky and a bit sick and a bit heady and maybe tired and you know their brains not working quite as fast and there's no, there's no sort of, urrrm, sort of different, they're not treated any differently for that, and I get that it's nice in one way to treat them the same it's also nice to appreciate that they're going through something different. Maybe, maybe, you know, ask them if they need a bit of extra time or be a bit more compassionate if the work handwriting is not that neat, or you know, that side of it.
	Sarah (Emily's interview)	151-158	Um, [child] was so unhappy she was coming home in tears every day and I was sending emails every day saying she's not making friends, she's not, you know you need to be supporting her when she is there, and they're saying, well, she's not coming enough and I'm like well because she's anxious and I couldn't force her in when she was crying and stuff about it and that that can be a trigger for [medical event] anyway, so it was all becoming like a vicious circle of she'd get anxious then she said have a [medical event], then she couldn't go in anyway, [sad laugher] it was just a disaster
		477-483	Um. When she was really small. I think they, they were willing to bend over backwards because she was cute and I think it was less important where she was at academically, it didn't matter to them so much, because maybe grades aren't so important at age or... I don't know but, as she's gone through the system and got older, it feels more like

			they've been more like, um, yeah, we know she's got this condition but, but almost less empathetic towards the impact it has on her
		490-499	there was an incident where [child] she'd had a trainee, not a trainee, a stand in teacher, so it wasn't her normal teacher and [child] had written backwards across the page which she quite often does, and the teacher thought that was really unusual but rather than like, um, tell someone or report it to me, they decided that she must have been being naughty and they ripped the page out of a book, and told her off. [laughs disbelievingly] and made her rewrite it all, and I was really crossed because I was like, if she's writing from the wrong side of the page. Something neurologically has gone wrong, because she is a really good kid and she just wouldn't do that.
	Sophie & Ian	225-229	Um, before he was head of year, he was like his form tutor for year seven and year eight. His best friend from university has [condition]. [okay] And so he understood. Umm, and he was the biggest advocate for [child] really, wasn't he? [yeah] to the point that if needed- you know there were times we couldn't get through to [child] to say you need to set this back, and he would say to him '[child] you know the time has come that you can't do this, you can't can go in' (mum)
		255-259	Ummm, and actually, she had quite a good working relationship with their school, because they had [child] and another girl in [child's] year, and quite a lot in one school - it's very odd that they do have quite a lot of children at that school. So they've gone in and done work with the school so the school were aware that what these children needed. (mum)
		602-609	She said the thing about his school is they were so open [pause] for the help. [mmm, yeah] And it was like come in teach us all, and she says we have other schools, I get a battle for them to even see me, or talk to me [yeah, mmm]. You know, you know, in some schools it's like, it's a brick wall you're the enemy, we don't want to know, and you know the poor children that are at schools, like that, you know is, is you think of, you know, what could they achieve with the support. Yeah. And they're not getting it and you know, a lot of it comes down to the scope of the school, and also the knowledge in the school. (dad)
		677-686	errr and some teachers would set homework, some teacher set homework, this is the lesson here's a bit of extra work to re-embed it this is your homework, where there's other teachers say, this is your homework and you need this for the next lesson, because if you haven't done it for the next lesson, well, you know, and he couldn't do thatSo it was a case of, you know, getting them to plan their lessons almost or to take account of that and almost say, this is gonna have to get done at some point. I mean, they've got very good eventually because there was some stuff like that and they would give it him and he could do it in the hub and stuff, [yeah] you know when he was out on quiet time but it was again, it was the teachers had to almost plan for his [condition] and the fact that he wasn't able to do homework, in their schedule [yeah].

		688-691	That might be one child, they're making adjustments for, and in their school there probably was only one or two in a class that needed a teacher to make adjustments [mmm, yeah] in a mainstream ordinary secondary school if you've got five or six or seven, that they're trying to make adjustments for that's an awful lot for that one person to have to do, isn't it. (mum)
The perceived Impact on the Child			
Sense of belonging	Sarah (Joe’s interview)	229-231	And when he went back to school, they'd all started making friends and friendships and stuff and he wasn't included and they were all playing football and things and although he was back at school he was in a wheelchair, um because he's so slow to heal.
		234-235	And um [pause] that was quite hard... on him. Um, and then they, we, we, we spoke to them a lot, at length, about how different [child] felt from other kids and how he needed more support in school
		285	And, and the other kids were horrible
	Sarah (Emily’s interview)	116-117	So we spoke to the incontinence nurse and they give these pants that, so she could feel like everybody else and it was much better.
		305-309	That's. I've never keep them off if they could be in school, because they want to be there. [Yeah] you know, they want to be there, they, they want to learn they want to be just like everybody else. Umm, and they hate feeling different. You know, so, but it singles them out,
		879-882	[Child] doesn't see herself as different. [That's really positive] She sees herself as you know, like everyone else when I said we're going to do this, she's like, 'Why?' [laughs
	Sophie & Ian	780-784	Because you have to make a plan as to what you’re going to do, and all his friends were going on about doing a levels and going to university. And for [child] it was like, I don’t think that’s – I don’t know what am I going to do? And I said to him last night. What do you think you’re going to do in the long term? He said, Well I don’t know because I don’t know what I’ll be able to do, [mmm] so he kind of thinks that he will do what he can doesn’t he. [Yeah], (mum)
Friendships	Sarah (Joe’s interview)	398-400	... I suppose the buddy system when he first joined to the school, they knew that he'd had problems, making friends and stuff, and they buddy him up straightaway and those are the friends that he's still got now, that, that, those first people he was introduced to. Um, so that's made a big difference

		533-537 572-577	Yeah, but I don't think schools, I think generally the schools don't realise quite how important friendship, because that seems to be the thing that's caused problems for all three of my kids with all their different things, has been friendship, and I don't think they realise quite how vital having those secure relationships are in school, for their wellbeing and their learning and their social learning, and the way their self-esteem and how they feel about themselves but his peers... I think they do see it more because they're more, the ones who are around all the time the good friends he's got now they see it. They understand that he's, you know when he's tired and he needs a bit more, they're quite compassionate and kind to him. I hear that they've been really supportive to him all that sort of thing, they really are good kids. And uh, they, you know, they give themself confidence
	Sarah (Emily's interview)	246-251 309-314 353-356 358-366 896-898	But um, yeah, so, she's just finished year six, and we'll be going into year seven, so I think the hardest thing to get across to schools, is the impact it has on her self-esteem and on making friends and keeping them, because they don't seem to understand how hard it is, from - I don't think they support them enough in, in their friendships, because even now she's got friends but only one or two, you know like, yeah, so that's hard it's less so with this school with the E praise points because, [mmmm] although it still hurts her. It's not so widely, You know it's not like widely known, whereas in the last school with it being a class reward. [Yes], If the class didn't get full attendance, it wasn't hard for them to work out who was to blame, you know. Yeah, it's horrible. Just awful. So,yeah Um, in her new school, they have a, [pause] they have this thing called the bungalow where they can go at break time, lunch time if they haven't got anyone to play with and they, they have board games so they can encourage them all to play together. Yeah, umm, and also just explaining. I don't know whether they, I encouraged them to explain um, about [child] to them to answer -to um, to her friends so they'd understand. [mmmm] I don't know exactly what was said. And I think if they had really understood that she, you know, might be tired and maybe we'll play a quiet game and stuff like that might have helped, because at play time they'd all run off and she'd be all achy and breaky and not go and join in. Yeah, it's, yeah it's really hard to know what the t But yeah, I think, I think generally, I think people see it as a bit, odd, like young, young, she's not cool. But that's because she's not there to know what all the trends are
	Sophie & Ian	514-517	It's quite interesting because [child] doesn't feel like - because he's left the school, and all his friends have stayed at the school at sixth form [mmm] uh and, but and he's gone to college so he's done something different. He doesn't

		984	feel like he's any more left out. The fact that he's done that because he was in school so infrequently that he's still in the discord chats and he's still in all the jokes because it's all done on social media. [long pause] they don't. [all laugh] They hear him on discord. [yeah, all still laughing]
Self-esteem	Sarah (Joe's interview)	153-155 344-345 608-610	Um, so that was one thing and [child], his whole confidence around the staff changed, [pause] he really didn't trust them after that, like, he was really upset that they accused him of waving his needles around I don't know whether they fully understand quite how traumatised [child] was by his last experience. You know that, it really did, It really did cause him quite a lot of stress. He doesn't really talk about it much, but I'm sure he has had that, because you hear it in the insecurities about what he's wearing and how he looks and whether they see it and and that sort of thing. Um, so I think, I think he gets more of it than he probably even tells me about.
	Sarah (Emily's interview)	110-112 246-251	I think we were in the 40, 40% range, and a lot of it was because she was unwell with [medical event], and because of the incontinence she was getting really aware of herself, didn't want to be there But um, yeah, so, she's just finished year six, and we'll be going into year seven, so I think the hardest thing to get across to schools, is the impact it has on her self-esteem and on making friends and keeping them, because they don't seem to understand how hard it is, from - I don't think they support them enough in, in their friendships, because even now she's got friends but only one or two, you know like, yeah, so that's hard
	Sophie & Ian	310 359-365	And it's, [I mean he's doing well] and he's doing well, so his confidence in himself went up. (dad) He's not showing his potential is he. But it's also quite distressing to him in, that the school that they were at, is very high performing, the children are expected to do very well. and I don't think [child] realised that it's not until he's gone to college in the last two or three weeks that he came back the one day he went, 'I really am quite good at things, you know', and I said 'well of course you are', and he said 'but I always felt like I couldn't do stuff, I always felt like I was failing'. He says 'I'm actually - I've realised that I'm quite able'.
Academic achievement	Sarah (Joe's interview)	116-117	when he was in school… Yeah, he was always doing, he was fine academically keeping up, we'd catch back up where he was

		312-311	But they, they've been, they've been so much better [Child's] grades are right at the top, he's at the top of everything. Um, they've really encouraged him so it's been good.
	Sarah (Emily's interview)	76-78 432-435 449-456 838	um, and they put her on a IEP thing, I think it's just means that she was a bit behind, so they were trying to bring it back up to where she should be. ummm, and, and that was fine. I think having the IEP was really helpful. She doesn't have it at this current school. [okay] So it's hard for me to know. I'm not getting that monthly like this is what she's done and this is the targets, umm, that - it was helpful for me to have it. I went in with a letter from her consultant saying that he really thought she should do with an educational psychologist because of [condition] and the effects that can have, you know, would just be worth... [yeah] And they said, Oh no, we need to form our own assessments. So we'll do that, and then the SENDCo there came back and said they were happy with [child] and they didn't feel that it was necessary and so she hasn't... she still hasn't had it, and I still think it would be useful I think she's in line with expected, whatever is on
	Sophie & Ian	300-302 333-336 353-354	from the perspective is when those online lessons started, and he was at home and he was learning, virtually every teacher said at that next Parent evening. His work has... [pause] you know his standard of work and his quality of work has gone through the roof, he is you know he literally jumped grades (dad) But I think his attendance between the beginning of year eight and the end of year, 11 was about 31%. [mmm] So when you look at it on that level it's actually - the fact that they come out with anything, is incredible, isn't it? (mum) It's so frustrating for him and, and almost for the parent because you know at the at the time he's not getting, it's not a reflection of him and his abilities. (dad)
School isn't for chronically ill children			
The battles	Sarah (Joe's interview)	131-139	That's fine, couple of weeks later they contacted me and said, Oh, can you send, can you ask for a prescription for safety needles, and I was like no, he don't need them. And they're like, Well, [other child's] subscriptions running out, right, who's that what, who's [childs]. and they're like, oh we using them at school he's using [child's], it's like, well, he shouldn't be using [child's] because he's not prescribed those like uses a normal, and they're like, No, he can't use his own needles in school. This is the first, I'd heard about it. [Oh my goodness]. I was so cross, then we discovered that, I mean [child] had been complaining about bruising on his arm, but I didn't really think about it until we worked out they were using these safety needles, and they're like a, autoinjector. And it was bruising his arms because he doesn't have the same fat level as the other children, so he was getting really bad bruising.

		143-144	they were literally like we won't have him. If he won't use the safety needles because of our staff and needlestick and safety.
		244-254	Umm, [sigh] and then they started on about his attendance at this point, he'd had a few, he'd had a sickness bug off that - they knew it was a sickness bug because he was actually sick in school. [Yeah] so, I got a phone call saying 'he's vomiting we've started his SOS,' that was all brilliant they did the right things, you know, we took him straight to hospital, he'd been in, but then I started getting these emails about his attendance, his attendance is, is low, Um, you need to come in and have a meeting, which I did, I went in and explained you know he's been in hospitals, his attendance, blah, blah. Then, I think it got down, I think at one point it was down to like. Because it's it done like on a timely basis Isn't it, so it's his first term, I think it had gone down to like 40 or something ridiculous, and they were, they were really, really lay, laying it on to us you know we're gonna get hold of local authority. This is a very, very low, you know, you must be sending him. Um, it wasn't just like a generic letter this was this was definitely - where you're, This is unacceptable, it reflects badly on our school, that sort of thing.
		259-263	Then, he was struggling to get - a bit like in the previous school, he's struggling to get to lunches, so they gave him a pass, fast pass, so you can get to lunch, earlier, um, to get to the front of the queue [mmm], so that you would get to the front of the queue. But then he lost it, so they wouldn't replace it, which seems a bit ridiculous to me, they were like, 'No, he needs to take responsibility', I'm like, I get that, but it's kind of important because it's hot food is, you know, quite crucial, and they weren't very supportive about, that at all.
		264-266	Umm... And then they weren't very happy about the fact that choice of kitbag he had he had like an Adidas bag and they were saying, Oh, it can't be, um, labelled and stuff. It's very hard to find a bag that will fit all of the medical kit. They don't come as standard, they don't give them out.
		427-432	They' won't let him snack, they'll only let him take his glucose, uh, dextrose tablets. [ah okay] So they won't actually let him have biscuits and stuff in his bags, which again is a challenge, as that would be better for him, dextrose does have carbs in it, I can't argue with that, and it is more medical, in that it is a tablet, but it is um, It's, it's more sugary, so it's also not good for his teeth and all that sort of stuff and it doesn't, it's just not ideal, but they [cuts out] it they're quite happy with because it's a recognised tablet for treatment of [condition].
	Sarah (Emily's interview)	331-338	So, yeah, that I don't think they do enough to meet their need for friendships I mean, they, they did this thing where they took her out for like Forest School, and that was lovely, but in a way it singled her out even more, and she again she wasn't with people she knew, you know, I don't know if they could, I don't know what, um, it's hard to know what I would have wanted them to put in place but, [pause] but I know that what they were doing wasn't working so, Yeah, it's really hard.

		630-641	And it isn't with these two, they just, you know, and I often think if they had a different condition, they would be more supported but it's almost like because they're the more invisible kind of things there. [yeah] And they slip through the cracks, they're not supported properly. And I find that totally unfair, but I don't know how to, I know and I know I can't explain how my experiences led me to that, it's just that is how it is. I know it is if there were, if [child] was in a wheelchair and visibly disabled I'm sure they'd give away more support, but because it's sort of, [long pause] ah i don't know, I guess it's not so [long pause] it's, it's that middle line that she toes, you know she can be really well for quite a long time, and then not. And I think that's why it's because it's so variable I think that's partly why it's so hard to get the right support in place, you know, it's yeah.
		718-738	I need them both off so I had a bit of a bit of a fight and had to get letters to even though had the government, one had to get letters from [childs] consultants, both of them the [condition] and the [condition] one. They had to both agree that she needed to be off for the school to support it, they wouldn't support it just on the government letter because of the changes they were like, Oh, well they might not have even, you know, got it right. So had I had to get letters from both of them which was not easy because most of those departments weren't even working properly. So, we had a bit of a battle getting that. ummm, and that was a bit tense for a while. The school were quite sort of keen that they come back in, and I was like no, and they were like well, if you don't we won't support you with online learning and I was like, you have to, [sigh] and they're like we only support online learning, if you've got a, you know, [mmmm] if you can really prove that they should be off, um. And that eventually, I can't remember who it was a spoke to, I think it was the deputy Headmistress, um. And I just said to her I know you're a mum, I know you've got kids, would you send them - you tell me to send her as a mum, and I'll send her. And she said well I'll go and speak to the head and see what I can do, and I don't know what she said to him, but they came back and said yeah they can both be off. So I was like yes, battle won, but it was a lot of... a long journey to get to that point.
		752-755	had to do that fight twice which is ridiculous you've done it once you've had all this stuff, but had to do it again. Yeah, yeah, they don't make it - it is a battle. Yeah
	Sophie & Ian	258-264	Umm, and I think probably because for us, we'd already had quite a battle to get the support our eldest needed with them hadn't we? [yeah, yeah]. So actually, they might have either realised that we weren't going to back down, [laughs] or they thought actually we recognise this. (mum) Yeah, we said, they listened, as opposed to before where we said and we had to fight for it, whereas this time we didn't (dad)
		288 - 295	The only real difficulty we had with school was when, umm. Because of the way that their school is set up, their compulsory GCSE is English, English, maths biology, chemistry, physics, [yeah]. So when [child] had to drop to the five, he wanted to keep computing, because, for as long as [child] could ever talk and walk, he wanted to do

			something with computing, and he wants to drop chemistry so that was the only resistance we ever had from them. Yeah, and they wanted him to drop computing and keep chemistry [yeah] didn't they, they got that he needed to drop to the five. [Yeah], but they did - they wanted it to be their choice of five and we were like no for [Child], we need to keep the subject that he's really wants to do. [Yeah] (mum)
Systemic issues	Sarah (Joe’s interview)	104-110	So he would end up in hospital and the most frustrating thing is, he's in isolation, because he follows him, or she, you know, say, you can't go to play rooms and the teaching rooms, but they still bring around the schoolwork and sometimes you know they're really poorly and they're bringing around the schoolwork, and that used to feel quite unfair, you know like they didn't seem to understand that there's a time and a place for schoolwork like maybe when you're starting to feel better towards the end of an admission but not right at the beginning when, you know, you're in high dependency unit as it is, but because he's conscious [laughs] and awake, they're like, yes, have some work, it's like, 'really? we're doing that now
		111-115	the work that never relates to what schools doing it's always like, ahh I don't know it is just completely separate to anything he'd have been doing at school, and then, he'd work on it, and then when you go that school they never seem to know about the work you've done in the hospital. So that was, that was a breakdown that and that is really upsetting because sometimes you've worked really hard and the school wouldn't even know about it you know, it's just like, what? It just felt like self-defeating, so that was quite hard.
		558-560	whereas I don't think teachers have that they just don't have that understand the human being side as well as I've treated the medical events now they can go back to being perfect, doesn't work like that
		577-581	because all just standard uniform, it doesn't really incorporate having a great pump, attached to a belt around your waist, and he doesn't like having the lump you know makes him, and i'm like ah, don't worry about it, he was thinks he looks fat, it's like, you know they reassure him about that sort of stuff, because I don't think the teachers or the people who design the uniforms. Ever think about that side of things [laughs], and it's all tailored to one isn't it
	Sarah (Emily’s interview)	87-100	So if they all, all the class got good attendance, I think full attendance, they got a classroom award which would be a party of their choosing, so they could choose to have either [pause] uh, a sports party or a or a film party or something at school. And they introduced this all the kids were talking about they're all really, really excited. And I said to school I don't think this is really fair because [childs] not going to be able to do that, even if she was completely well, she'd still have her appointment she has to attend in clinics, and that's, that means it's unachievable. But they, they stood by that they, they, you know, the government want good figures and its their policy to reward attendance and yeah so that was when she started to have problems fitting in at school - she'd

			have time off and then they'd all be cross with her, and then people didn't want to be her friends [trails off] Yeah, so that was hard.
		118-112	we started getting them these letters from school about attendance. I've had them before [laughs sarcastically], with the other children. But, umm, you know, saying, 'Oh, it's really low, we're gonna have to speak to umm the governor's and involved county council', umm,you know, umm you need to improve your attendance type of thing.
		204-209	it's gone really really well with that school, aside from, we have had the generic letters about attendance [laughs]. They say, they always phoned me and they say we're really sorry but she's got to bring a letter home or we're emailing your letter. Please don't worry about it you know we have to generate it so they, they kind of take that, that view which is really helpful.
		471-476	It's been really hard, I keep, I feel like [pauses, stumbles over words a little] [Child] isn't disabled enough to be termed disabled, you know, in the eyes of, in the eyes of the school SENCO [yeah] so she's not on an EHCP, you know, but then she is disabled enough to get DLA and be, you know labelled that way, but not an EHCP and she's not [recording cuts out].
		484-489	I think it comes down to funding, you know, they didn't want the educational psychologist I think that cost them money, they, they referred her to, they did refer her to um the paediatrician [mmm] at the Development Centre, who had a look at her and said, all these are school related issues so really this is for the school to deal with. [laughs] So they just bounced her straight back
		630-641	And it isn't with these two, they just, you know, and I often think if they had a different condition, they would be more supported but it's almost like because they're the more invisible kind of things there. [yeah] And they slip through the cracks, they're not supported properly. And I find that totally unfair, but I don't know how to, I know and I know I can't explain how my experiences led me to that, it's just that is how it is. I know it is if there were, if [child] was in a wheelchair and visibly disabled I'm sure they'd give away more support, but because it's sort of, [long pause] ah i don't know, I guess it's not so [long pause] it's, it's that middle line that she toes, you know she can be really well for quite a long time, and then not. And I think that's why it's because it's so variable I think that's partly why it's so hard to get the right support in place, you know, it's yeah.
	Sophie & Ian	139-145	And she said, uh,put him in a taxi and send him to a taxi for school, [yeah] and we were in one of these catch 22 situations where, because he's because he's ill and he can't couldn't go to school because of his illness, the council should fund it, but the council wouldn't fund it, because he wasn't at his nearest school. [ahhh] So if we took him out of this school and put him in the nearest school that was doing a completely different exam system than him,

			they would have funded a taxi but they didn't. So we just bit the bullet in the end and we started sending them by taxi (dad)
		164-182	But the other thing you're always wary about with [condition], is our exam system doesn't exist, uh, doesn't, doesn't fit with the [condition] pattern because you've got no control over where your exams are. So, if you, if you get your exam timetable and this is exam week, and you've got [condition], If you've got your maths and your English. On Monday, and you've got two exams on a Monday. Yeah, whatever you've got on Friday, you're going to do crap at. [Yeah], sorry, on Wednesday, because it's gonna, it's gonna, it's gonna knock on, whereas if you just had an exam, like. If you had one exam on Monday, one exam on Wednesday, one exam on Friday. Yeah, you would get. What is it, now, it's numbers, [mmmm] you know you might get three eights, yeah, if you had two exams on Monday, and one on Friday, you might get two sevens and a five. …You're always it's always that constant worry in his mind if you see what I mean [yeah], you literally are throwing the dice. [Yeah], because, you know, an, and it's where the exams fall and, You know and it's.... So yeah, that's always a constant worry, I think, for us as parents, and for him as.. yo, you know he's aware of that he knows if his exams go Monday Tuesday Wednesday. Then, two exams on a Monday, two exams on a Tuesday he knows he ain't gonna, that he's, He's going to be there going, I forgot my name on Wednesday. [all laugh] Despite the fact that in the pre-test he's been getting A star, A star he's gonna be rubbish, you know. (dad)
		323-327	because of the way that you know how the curriculum works in schools, it's this circular curriculum where you learn the subject and then you come back to it eight months later and build on it. And because he'd had missing. The year before sometimes they'd come back to the subject, and he's got this is a complete new subject he can't build on this I've never done this, because It just so much happened that those were the lessons I was away, and he you know, he always had complete blanks (dad)
Being left out	Sarah (Joe's interview)	88-92	with PE and things we wanted him to join in, We had a bit of reluctance, when he first joined school with them worrying about getting the balance right, because there wasn't really enough information from the hospital for them, they weren't happy with, 'well, how much does he need before he exercises', well we don't really know because it depends on the exercise he's doing and how hot it is... so they were quite worried about, including him in sport
	Sarah (Emily's interview)	135-142	[Child] was getting really upset about thing's like she was going in, and she'd have missed one part of a lesson. So, I don't know, [stumbles over words] in whatever they were doing. And then the next bit would be something fun like making a mask or doing, ummm, one of them was a food thing, and they were saying oh you can't do it because you haven't done [pause] the paperwork beforehand, you know like the school bit. And um, then she would say, well - but they weren't sending it home, you know?

		252-258	and she couldn't join in with things like swimming because they wouldn't put a one to one in the water because, oh, I can't remember why, they had a reason that I checked through all their school policies and yeah so she didn't do that and she hasn't been able to do food technology for similar reasons. Safeguard, you know, health and safety concerns [laughs], which is really sad, because that would be her probably favourite lesson
	Sophie & Ian	488-491	uhhh, It's like they asked him out you want to come 'No I can't come' 'No I can't come because I'm not well enough' 'no I can't come'. And after about the eighth or ninth time they stopped asking (dad)
		843-847	but then he had his heart set on this geography trip because he's always loved geography, They were gonna go to Norway. But, you know he's his little heart was broken when all his mates were going on it and he couldn't and he didn't bring the leaflet home and we said 'oh have you not brought that leaflet home', you know, and he was like No, I didn't bring it home because I can't go'.
The punishments	Sarah (Joe's interview)	157-160	He was missing, lots of break times because he was low and [pause, strumbles] the way that - they wouldn't take him out early to test him they wouldn't let him go. I wanted them to go like 10 minutes before break, [yeah] and they wouldn't let - that was too disruptive. So he's missing break time, which meant he was missing time with his friends. and, yeah, that was really hard
		195-204	I was like what's the matter and he said, 'They did my injections, all day, every two hours in my fingers.' Now, [child, child] has to have his blood sugar's every two hours because that's, that's part of the [CONDITION] he needs to have more testing, but he's got a sensor, so he doesn't need to have the blood tested in his fingers, unless it says he's high or low, and they've literally made him do it in his fingers all day it was like, and he said, This isn't right. This is not what my care plan says, and they were like, No, this is we're doing everything by the book we're doing everything, they were. And he said he wanted to phone me and they wouldn't let him ring me, and that was it. I, I, I phoned up the local authority and said I'm going to remove him from the school because the safe - I think that's safeguarding, that's abuse you don't, you know, you don't need to unnecessarily give someone medical treatment that was just well out of order
		219-224	we got a phone call to say that he been - done his blood in uh, inside a Science Lab. And I was like ...yeah? No, like you're not allowed to do that. Well we didn't know he wasn't allowed to do that, he didn't know he wasn't allowed to do that, and he'd been given detention. He was absolutely distraught because, you know, he'd been really made to feel bad by the science teacher who said that it was contamination risk and they'd really laid into him and I was very angry about that
	Sarah (Emily's interview)	87-100	So if they all, all the class got good attendance, I think full attendance, they got a classroom award which would be a party of their choosing, so they could choose to have either [pause] uh, a sports party or a or a film party or something at school. And they introduced this all the kids were talking about they're all really, really excited. And I

			said to school I don't think this is really fair because [childs] not going to be able to do that, even if she was completely well, she'd still have her appointment she has to attend in clinics, and that's, that means it's unachievable. But they, they stood by that they, they, you know, the government want good figures and its their policy to reward attendance and yeah so that was when she started to have problems fitting in at school - she'd have time off and then they'd all be cross with her, and then people didn't want to be her friends [trails off] Yeah, so that was hard.
		135-142	[Child] was getting really upset about thing’s like she was going in, and she'd have missed one part of a lesson. So, I don't know, [stumbles over words] in whatever they were doing. And then the next bit would be something fun like making a mask or doing, ummm, one of them was a food thing, and they were saying oh you can't do it because you haven't done [pause] the paperwork beforehand, you know like the school bit. And um, then she would say, well - but they weren't sending it home, you know?
		209-215	Um, the, the, yeah, I, the only thing they still have the stupid rewarding attendance thing [mmm] it's slightly different there, but they have the full attendance, and you get E praise points. So for every week that you're in for full attendance, you get 100 E praise points which is quite a lot. And [pause, voice breaks] she hardly ever gets them because she's not, you know, [mm, incoherent words] and then that really upsets her because she really works to those.
		285-298	I get really emotional every time because they are heart-breaking because they make it like it's their fault, and, [yeah], and they're being punished for something they cannot control I mean they say they're not punishing them but by not giving them a reward [pauses, emotional]. How is that not a punishment, it's like every kid wants the reward, [yeah] and that that I find that really really hurtful, is that they celebrate, and then they like celebrate the ones with the highest attendance as well and they're like, you know, they call them out in assembly and they're just like that. Yeah, it's just beyond their control, and also I don't like it because I've heard so many parents say, ah well they didn't want to get bad attendance so they, I sent them in they just got a headache, they'll be fine.
		389-404	because she's behind in Maths and English they take her out for that. [Yeah] and I understand that they have to because they're core subjects, but they take out of art, and the other things that she loves. And it's like, [exasperated sigh] that's heart-breaking because she hates those subjects, you're taking her out of the ones that she's good at and she loves, to do what she's not good at, but you can't argue with them because their core subjects so they have to do it. [yeah] I wish they wouldn't take them out. I'd even rather she stayed and did a little bit, because she misses art and that's her favourite. [yeah]. Yeah, we, that's, that again is this kind of like a little inclusion thing you know, because those are the subjects where they're more able to talk freely and, um, move

			around and bond and she's not in it because she's having... So, I've tried to say that to them but it's they've immovable on that because it's the core subjects you can't, they won't change it. Yeah, they're like, when it fits in, and she needs to catch up, and I get that, but...
		490-499	there was an incident where [child] she'd had a trainee, not a trainee, a stand in teacher, so it wasn't her normal teacher and [child] had written backwards across the page which she quite often does, and the teacher thought that was really unusual but rather than like, um, tell someone or report it to me, they decided that she must have been being naughty and they ripped the page out of a book, and told her off. [laughs disbelievingly] and made her rewrite it all, and I was really crossed because I was like, if she's writing from the wrong side of the page. Something neurologically has gone wrong, because she is a really good kid and she just wouldn't do that.
	Sophie & Ian		
Despite everything…			
Home learning	Sarah (Joe's interview)		
	Sarah (Emily's interview)	236-245	I think [childs] attendance at the moment is like, 86.2, I think at the minute, which is pretty good, for [child]. Um, I think being -actually shielding works really well for [child] because she's going to bed on time, she's not stressed. She's - all that side of things, I think have made a big, big difference because, she's been so well. Other than the actual shielding [laughs] she's had much less time and um days off and also the masks wearing, when they did go back, I think that's stopping them getting as many bugs because, [yeah] they do tend to pick everything up. So I, I think that her attendance is actually better than it's been, which is [laughs] So, the other way round to everyone else isn't it?
		847-863	Yeh, so this year, what, um, She came on, she came home with two certificates at the end of school one was, was a one, one was something like the i think it said that she made the most progress in the in the in a year. The child who'd made the most progress [aaaah] And I think, honestly, I think it's because we did online learning. [Yeah] So, I think it was because she was concentrating better, because she wasn't worried about her friends and stuff so she was more engaged, also because it was right in front of her, and I was there to ask questions to whereas, so I would repeat things and she could pause the thing and go back to the beginning. Every time you know? You forget something, just go back and listen to it again, but she can't do that in a classroom setting [mmmmm]. So I honestly think it was things like that that really made a big difference like if she's struggling to concentrate you could leave it 20 minutes, and then come back to it, when she's fresh and do it again and be fine, which um, she can't do at school. So that worked really really well for her learning at home, um. but she's just so wants to be part of everything, you know.

	Sophie & Ian	300-302	from the perspective is when those online lessons started, and he was at home and he was learning, virtually every teacher said at that next Parent evening. His work has... [pause] you know his standard of work and his quality of work has gone through the roof, he is you know he literally jumped grades, (dad)
		344-346	I could, I can say, hand, hand on heart, I think, if [child] had had online lessons. Umm, for the whole of [long pause] his time, [mmm] he would have got more than five. [Yeah, he certainly could've] you know, and you know, he, he probably could have done everything (dad)
		538-543	course he would just get up, log on for registration, do his lesson and then as soon as he finished the work. he's turn his video off, turn his, you know, if you finish the work early or, sometimes he wouldn't have his video in any way he turned the sound off and you just lie on his bed and you know it's still been the lesson but he done the work, [yeah] 'cause he was clever enough to have done the work. And wait till the end of the lesson, and it did him the world of good, he was, he was a different boy
Rewards and recognitions	Sarah (Joe's interview)	303-305	Um, and they rewarded [child] for for the things he does do really, really well like they found all the things that he was really good at, and sort of, um [pause] rewarded that when they got another [condition] child come into the school, they let [child] go and talk to him and, and give him advice
		393-396	He's had quite a few of these ummm, achievement things sent home so he got a, he got a specially awarded little badge for kindness when the other [condition] child was diagnosed, because he given lots of advice and stuff, so he got that, and he got a like um, a head teacher Recognition Award for um, for perseverance and stuff, which was nice because it kind of hinted that we know, life isn't always easy, so that was lovely
	Sarah (Emily's interview)	215-222	Um, In fact, she rarely got much sort of, ummm, sort of, well done, praise and stuff but since the lockdown learning that's been different, because suddenly she's getting letters like, um, saying that you're one of our, our work heroes and you're trying your best and suddenly we're getting, you know, brilliant engagement, top learner, all this stuff which we never have before. So that was really lovely but it's sad that it's taken them actually all being off for them to recognise that she does work really hard. [Yeah] um, [pause] because we were doing it before, but weren't recognised for it but suddenly when everyone was like oh yeah you're doing really, really well, well done
	Sophie & Ian	934-940	and his head of year said to him look [child] we've heard so much about resilience in the last couple of years, COVID and everything else has gone on, he said, nobody's demonstrates that more than you have to get through what you've fought and to get to where you are.[yeah] Um, and then said to him you know if you want to come back when there's events going on, you're always really welcome which actually made him feel really like it was worth it, wasn't it? [mmmm] So they know that he will do well, they know that he's able and um, determined [determined Yeah.]

Adaptations	Sarah (Joe's interview)	81	So, um, all the classes had a snack box, which he could, we encourage the teachers to try and get him to eat.
		367-372	Yeah, um, I think the key things that I think have really helped [child], in this school, they haven't had like a TA because um, they don't emit, they don't, they didn't have enough. Yeah, he doesn't have a TA, but they've had, but the medical staff is kind of acting like one, you know, they've, they've consciously made the point of being around and popping into lessons and so he's kind of had a more like a key worker adult who knows him, and that's made a big difference, somebody who, who he knows gets it, that's made a big difference.
	Sarah (Emily's interview)	53-54	by the time she started school, they wanted to put in a, you know like a school care plan so that everybody knows how to respond to the [medical event], so that was good
		63-70	ummm [pauses] school were pretty good at that age with her, that she would be wet, they would deal with it. It wasn't a problem at all. They didn't mind her being off sick, you know, they were always really supportive about it, it was, you know, it was just part of who she was, and um, they were actually quite good at trying to make sure that when she went back into school, she was working in groups and things with her, like, closest friends, so that really helped her sort of get back in to school and get - enjoy it more.
		72-76	they introduced beanbag corner for her so that she, if she was having a [medical event] or she was tired afterwards they could put out on the beanbag - mostly she would just fall asleep
		225-236	They had to shield, a lot longer than the other kids who went back, um, and I found that a bit hard that they didn't, they uh at start, to start with, they just, were giving them the online learning, but all the videos stopped. So I said to them, you know they're missing their classrooms, and I have to say the school were amazing. They, um, made it so that they could [pause] be live in the lesson so the teacher had them, like a computer on the desk, and so they could be part of the lesson. um, but the rule was, I couldn't be present at all for any of those video calls because that was safeguarding those children in the, you know, so that was fine, um. So yeah, that, that was really lovely because they, their friends knew they were there and they could interact and that worked really really well. So on that side of things
	Sophie & Ian	128-133	So, the one - the thing that made the biggest difference for him is because he couldn't do full time school eventually school cut him down to a part time timetable and his options of what he took was almost. We almost looked at the timetable and looked at what we could cut out to try and [pause] bank things together, [yeah] so that he could go in for a morning and come out, and it was like well if we drop that and we take this one... It's good you're gonna have a much better Wednesday and week like that (dad)

		187-198	... I mean school did make some adjustments for him because he was allowed to sit exams... If he had an exam, when the, when the what they were going to say, what they'd said but obviously because we have the, the lockdown and the assessed grades, what they had said is if perhaps, if there was an exam on the Monday and an exam on the Tuesday, sorry I mean two exams on the Monday, and there was kind of, you know, an hour off for lunch, what they could do with [child] was, they were gonna sit him in the one exam. And then what they could have done was kept him in isolation, so we'd have had the sandwiches, and he could have had like a two hour rest and started the second exam, [later] a little bit later actually, and finish it a little bit later, you know, as long as he didn't mix didn't have his friends, so they could make some concessions, but of course it's the same day, you can't say. You can't say, you're going to sleep in this room in school. Wednesday, Thursday [laughs], and the exam that's on Wednesday, you can do it on Friday, but we'll just keep doing these little isolation bubble, it's, that's not going to work is it? (dad)
		241-249	Yeah, school set, school were very good, they, they set up - this was prior to, to [child]. They set up a hub, which was basically a room that children with special needs or they needed to rest. It was actually set up for our eldest son, who's actually got Asperger's, uhhh, and he needed a uhhh GET AWAY, desensitise, room, [yeah] uhhh, but because that existed when he needed to rest he could go there and it was a place that was kept quiet, [yeah] but it was still a room that had other, children in, that there might be quiet talking in so, i, i, it, it's not resting like resting is at home when you can just lie on your bed, close your eyes. Completely rest, well you know yourself is that if you're tired, it's rested, its resting by going back to your room, and I'm going to kip on your bed or having to rest on your bed or trying to rest in the canteen at lunchtime, you know, having the rest, [it's not the same is it] is not the same is it. (dad)
		544-549	and, uhhh, we are very lucky in that way in that [pause] I think because we've had the support, because we've had a teacher that fully understood it, errr, and with a bit of lockdown he's ended up getting really good results that he deserved and if he hadn't had that teacher, he hadn't had a school that had this quiet zone hub, and would have been acceptable to the part time and stuff like that. I honestly think he could pass, [mmm] he, he, he'd have nothing now. [mmm] He would have no qualifications I don't think he'd have got no GCSEs or (dad)
		573-575	one of the things that has really helped is, you know, it's this quirky little grammar school, It's not like any other school that you know, it's ethos is to put the pupils first, not the you know the pupils well being (dad)
		594-599	Because if he's well enough, he'll go to college or school, and he doesn't need a one to one support, he doesn't need a scribe, he doesn't need all those extra things [mmm]. But if he's not well enough, there's nothing else you can put in case it's going to help him, apart from the online stuff, because he's not well enough to go in anyway. It's all or nothing, Isn't it? [yeah] it's quite a difficult balance. (mum)

		639-641	just put him at the end of the row, [yeah] stick next to a wall, you know, some, some schools, you're in alphabetical order, that your desk, you know [laughs] but it is simple things. (dad)
		865-867	And actually, we said well [child] can come to Harry Potter world but he won't make school for the rest of the week. [Yeah], so his head of year agreed that actually if [child] really wants to do it, then that would be a really good thing to do (mum)
The emotional impact			
The emotional impact	Sarah (Joe's interview)	209-211	I was furious that they would ever treat a child that way, just to cover themselves so, I just think there's no excuse for that, so that was horrible.
	Sarah (Emily's interview)	100-106	And then I think it, that knocked her self esteem. So then she didn't want to talk when she went back into school and she was having [trails off, long pause]. I think that, I didn't notice it particularly being her mum, I think because I would see her all the time, but at school, they said that she was talking very slowly and her friends that she did have, didn't want to wait for her to finish talking, so they'd either talk for her or get bored and go off. So more and more, she wasn't wanting to be there.
		176-181	we eventually managed to get her tested and she has got the [condition] disease so that would explain all the things that we were seeing. So we were keeping her off for, that they were saying was anxiety, they were actually real, they weren't in her head. So that was good, in the way that it made me feel validated I always knew I wasn't keeping her off for no reason [yeah]. But that I think the school treated me as if though I was.
		409-412	I've always found that really difficult because sometimes when teachers talk to you they always talk to you as if you've got no understanding of how school and education work.
		541-545	So I kinda know what to do, but it's it's really draining and that's partly why I didn't do the EHCP for [child] once I knew the school wouldn't support it because [older brother's] took six years to get, and a lot of fights, and we got it in the end, but it's not easy to [yeah] get evidence for everything.
		547-549	Yeah, it's really difficult, because I know we should be really pleased that she's doing so well especially when a lot of people in her clinic aren't so you sort of feel like you can't moan too much as well because we've got it.. Good.
		727-730	got a, you know, [mmmm] if you can really prove that they should be off, um. And that eventually, I can't remember who it was a spoke to, I think it was the deputy Headmistress, um. And I just said to her I know you're a mum, I know you've got kids, would you send them - you tell me to send her as a mum, and I'll send her

		763-769	Yeah, all my friends think all i do is go on about schools. [laughs] I reckon I've got PTSD when it comes to schools because it's just traumatic [laughs]. The whole thing's been so traumatic, it's horrible. I genuinely when I have to speak to school, get really anxious because you just don't know how it's gonna go like hate doing it, hate it. I get all my emails proofread, like by my friends to say does this sound alright, I don't know if I should say that or not.
	Sophie & Ian	29-30	he was the youngest in that belt in the county at one point he was seven and a half when he got his black belt (mum)
		373	But the reality was we had to say no because he wouldn't manage it, because he can't, you know. (mum)
		727-730	But that isn't what he would have got if it wasn't ill [yeah] and that's the thing that's less than his potential. [Yeah], He's got excellent results. Don't - you know they're, they're fantastic results and they're more than enough for what he needs in the future, but that's not, not what [child] is capable
		835-839	Yeah, because you know if he did bring them home we'd go well maybe we could do the, you know, and you'd start to talk about. If you could make adjustments and maybe he could go because you knew, he really wanted to go, yeah and he did, but deep down he knew he wouldn't manage it, and he didn't want to get the hopes up and stuff like that, so he stopped bringing back things anything
		950	I think they feel it's almost, like it's cheated him, of what he could have done isn't it?
		1077 - 1080	I think I feel sad that he can't do what other people can do I think it's really [long pause] sad isn't it?, [yeah]. You know, he's, he's not able to do the things that- I feel cheated for him I suppose. You know, even down to the fact of having to leave school and go to college means he's had to stop his music, so he can't. [oh] He can't play his saxophone and can't pay his piano, because his lessons and things all tied into school. [Yeah
Being an advocate	Sarah (Joe's interview)	152-153	And I was like, I wish I had gone to the governor's before but I didn't know how the systems really worked and I, I had never thought of doing
		212-13	So, we did, we went through with that plan, the schools are connected, you know they like, follow up from each other, so they all [pause] know each other. We went in, we explained the situation with the school
		234-235	And um [pause] that was quite hard... on him. Um, and then they, we, we, we spoke to them a lot, at length, about how different [child] felt from other kids and how he needed more support in school

		289-290 348-352 479-485 492-494 777-779	but it got so, he got so low, I just thought, if schools this much of problem we'll move, and that's, so we went to [school] because [sister] had moved to [school] from the primary Everything's been left to me to manage. They said that normally urr, without COVID the kids go up there, um, and they will get a staff handover, but as yet they hadn't - when I went in, which was the last week before term finished, they hadn't had anything not, nothing at all about [child] over. So if I hadn't chased it, they wouldn't even have known he had medical stuff before he... so I, I chase all that they also know that, that school is the best place for them because I can't teach them, that stuff I wouldn't put them, I wouldn't send them if, and they also, I think they know that I wouldn't send. If I was, was, if I, if I thought the school weren't working with me, because I've moved them, whenever there's been a problem. I've moved them I said right, that's enough, you know, I'll work with a school and try my best. If it isn't working. So they do know that, yes I have to send them. Yes, the law says I have to and I'm doing it because it's in their best interest. They also know that they come first and if it wasn't working, I'd move them I'm hopeful for this new one that it will be good. But if it isn't, then we'll face those problems and we'll find a way of making it good, cos that's what I do [laughs]. That's my job as mum to make sure it's gonna be okay. All the other children will remain in school, and will be tested daily or something and I'm like, if that, there was a positive case in their class I'm taking them out, like, I don't care if so
	Sarah (Emily's interview)	145-147 196-200	So it was, you'd lose complete track of what was going on in school unless I asked my mum friends and found out from them what they were doing one of them suggested we try and go on the parent support group for the school, and introduce ourselves and see if anyone wants to meet in the holidays, which we did and we met a few parents beforehand with little children that came around to play with her so she knew some people before she went in and I think that was really good advice. That really helped.
	Sophie & Ian		
Am I doing the right thing?	Sarah (Joe's interview)	155 192-194	Um, and [exasperated sigh] yeah so that was that was difficult but we kept going.

		206-209 486-487	But this was literally a few weeks before he the end of school, and he had this big performance to do and he had this holiday, that he's really looking forward to. So I was like, okay, we'll still send him, it'd be, we'll still send him, it's probably just a mistake. It's not great, but we'll deal with it, and we'll send him in We left - that would have been end of year six, but it was the most heartbreaking thing to do because it meant he missed out on the holiday, and the things that they were really looking forward to. Um, It was really hard. And, and yeah, - you get all the flack from all the other parents don't you, and 'are you overreacting' and I was, I don't think I was its his safety at the end of the day, and I totally didn't trust them after that .So, I try and get the balance right I don't know if I've done it right or not. You know, it's really hard sometimes I think or do they, you know, have I passed my distrust on, a
	Sarah (Emily's interview)	525-532 550-556	I asked to do a Parental Request for an EHCP, which they turned down because they said that there wasn't enough, um, the school said they wouldn't support it. It wasn't actually turned down their school said they wouldn't support it and I lost my confidence to do it [pause] and just thought [exasperated sigh], I won't do it then, you know, because they're like oh she's lovely and she's doing really well and she doesn't need it and I still think she should have it so that, for me, so the social side more than anything else, they need to do. i worry I'm not doing enough as her parent a lot, I worry that one day I'm gonna look back and think I should have done that sooner. I should have got that help sooner, but then I also worry that, Am I seeing things that aren't there because of what's going on with the her brothers and stuff, so it's a bit of a.[long pause] It's hard. It's hard to know if I'm doing it right or wrong, I just have to trust that the school will pick up on it if she's not. Yeah, they seem to think it's okay so
	Sophie & Ian	481-482	And you have to let him do normal things because it's part of being a young person, isn't it? it's not right not to. Yeah, I'm not gonna say to him you can't ever go out with your friends [child], or you can't, you know, come up to [city] to see our family with us because that's not right.
Hopes, fears and the future			
Transition	Sarah (Joe's interview)	314-315 348-352	The transition to this new school is causing a lot of anxiety, because of the failed transition to the senior school last time Everything's been left to me to manage. They said that normally urr, without COVID the kids go up there, um, and they will get a staff handover, but as yet they hadn't - when I went in, which was the last week before term finished, they hadn't had anything not, nothing at all about [child] over. So if I hadn't chased it, they wouldn't even have known he had medical stuff before he... so I, I chase all that.

		511-514	And maybe uh, uh, when they come back from being in hospital, or being off for a while maybe like, uh, you get back to work interview maybe like that just to sort of say, you know, how you doing, anything you need different now you're back and it just sort of, that might be helpful, or is there anything you felt you missed that you would like to cover.
	Sarah (Emily’s interview)	534-538	I think that transition to, I think a lot is going to come out from that, that maybe is being masked by the fact that she's younger so that she's not having to take responsibility for a lot of things. I think that all will show. I don't think we're going to be out the water for a long time.
	Sophie & Ian	593-594 621-625	but actually [child]'s needs aren't massive, he's either there or he's not which is what we're currently trying to explain to college. (mum) but actually he said since he's gone to college, 'the kids are messing around in my class. mum' which is a new phenomenon to [Child] because it just didn't happen at school. He said, 'I don't like it I can't because there's too much going on', he's finding that quite difficult, isn't he? [yeah, mmm] Because yeah, that's, that's something he wasn't really used to
Into the unknown	Sarah (Joe’s interview)	320-329 629-631	there's a few things he said they made me worry… we'll cross that bridge, as and when, I think there might be a few battles coming up, just from some of the things he'd said Um, I think it will depend on how he's treated as to how he comes out the other end of it, hopefully they'll be nice to him, and encourage him, because he has the potential to be really good at stuff
	Sarah (Emily’s interview)	1000-1006 1014-1019	Oh I don't know, it could go either way she could grow, if, if, if things carry on going well, and she's, then she could grow up and be [medical event] free with medication and hopefully have a good job, or, but [pauses, stumbles] then it might not work out that way, I don't... Sometimes we think we'll end up with all kids, living with us forever [laughs]. So we've like planned for that, but ummm, I hope that she'll go on to be independent. Yeah, I just, I try and just get through each, each age stage as it comes and, not to think too far into the future, I think it's a survival mechanism, it's weird when someone asked me to think like that. I'm like, ooooh. Yeah, I'm so used to just like one head down, keep going. Yeah,
	Sophie & Ian	1201 - 1209	The reason we did that is we live just we live near [COMPANY], and [COMPANY] is just building a huge big cyber security bar er, base. And because [COMPANY] is civil service. They have a quota for disabled people. [yeah] So there is more chance of him getting a job at [COMPANY], if his [condition] is so bad he can only work part time

		1216-1219	[Yeah]. errr, and if he goes for an interview [recording skips] - A lot of people are gonna go, no job, that's it. [COMPANY] he'll still got a job. [Yeah], so we're, we're already thinking ahead for that, and we're already looking at that as ideal, I think that is, A I quite local, [yeah], errr, it's on a direct bus route, so it's not too far to get to if he is not driving, errr and they will be acceptable to having an employee that could probably only work part time, and that could have, you know, and that there's got a disability. So we're already ahead of that aren't we, and err, that's been our thinking, [and he understands] and he understands that, which is why he's done this course I don't know if [pause] you know I'd like to feel that he can live independently. There is no reason why, if he monitored his energy, he couldn't be independent. He is far more independent, in many ways then his brother. Um, you know he's quite capable of cooking, washing doing all those things he would just need to do it very carefully.
Thriving not surviving	Sarah (Joe's interview)	332-333 637-639	But I think, I think overall, they're going to be, they're going to be re - pretty good. I think there'll be pretty good they seem to. They seem to say that, the chi - getting to each individual child is most important thing to them I think it will become easier as he gets older, more knowledge out there now than there ever was. And that's half the battle.
	Sarah (Emily's interview)		
	Sophie & Ian	1028	]. So yeah, I think he, he's just great 'cause I think he can do some stuff that he couldn't do two years ago (mum)

Appendix N – All quotes organised by themes (children)

Sub theme	Child	Line number	Quotes
The adults around the child			
Relationships with staff	Joe	211-219 219-228 250-258 277-278	... and then also with the teachers and the needles... Umm. It was, I feel like it was forced, and I did not like it at all. And so, after a long time... They, I left because they, because after that incident with the needles and after that, I went in for another one day to, to see what would happen. And, yeah, they made me prick my finger a lot, and they also said that the teacher that was going to supervise me at PGL, which is where we were going for like the end of the year, wouldn't anymore. [Okay] like, they just would not look after me Even though, just because they got in trouble for what they did. And that, um, really annoyed me because I thought that we were good, with each other... because she was actually a quite a nice person. She just didn't learn and then she obviously got in trouble, a little bit, and then took it out on me in a way. And so, I've never seen her since. I hope she's okay and everything but it really hit hard, and I kind of lost my trust, in people. [stumbles over words] I kind of got close to especially adults. Cos it shocked me that they would like try and lie [oh go on, child]. Try and lie about like not doing something that and trying to get me in trouble for it [mmm] it got... quite bad in that situation. So, I just didn't think that it could turn out that way. Really, Well, so, when I went into year seven I was quite sceptical after that. So I never really wanted to interact with any of the teachers, so I kind of laid back, which worked until I really stood out because of, you know, putting my hand up trying to go out and then doing my bloods where I wasn't supposed to on all of that stuff. And then I got in trouble for it and I., that's kinda the breaking point where I just didn't want to speak to any adults I didn't really know and trust. [mmm] So it took a long time after that, like, after I came out of that school and after the therapist, who didn't really help too much for me. Ummm, because, uhhh [pause] I can't remember. It took a while to rebuild that

		347-350	And the teacher, my teacher was a science teacher, so he had a little bit of experience in the [condition] field. [mmhm] And so he knew a lot I actually got to go around, talk to the head of the year, who also did all the therapy and stuff for the, um, kids. In that year, And it was actually really good because - and it made me a little more clear about it
	Emily	349	I think they might be helpful I'm not sure I don't quite remember
		365	I didn't really like the teachers.
		371	I don't know I just didn't like them. Just, just didn't get a good feeling.
		682	Uhh, I probably wouldn't want to tell them.
	Morgan	584	Yeah. the student help desk do too.
Staff knowledge	Joe	78-79	and my teacher is just like, he's got a medical condition, you're just lazy
		218-228	Even though, just because they got in trouble for what they did. And that, um, really annoyed me because I thought that we were good, with each other... because she was actually a quite a nice person. She just didn't learn and then she obviously got in trouble, a little bit, and then took it out on me in a way. And so, I've never seen her since. I hope she's okay and everything but it really hit hard, and I kind of lost my trust, in people. [stumbles over words] I kind of got close to especially adults. Cos it shocked me that they would like try and lie [oh go on, child]. Try and lie about like not doing something that and trying to get me in trouble for it [mmm] it got... quite bad in that situation. So, I just didn't think that it could turn out that way. Really,
		260-263	but they kind of, it was as if they were at school for a bit as well. Learning about my, uh the disabilities, and about how to notice it. And now, I'm fairly good friends with them. like i said, I trust them

		281-288	So with the first about month or two. It was more just them watching me, learning about my, my, learn about what triggered it, what might be happening and it's a lot better because they didn't tell me that they were doing this, and so I didn't really like get scared that they would, you know, blurt it all out and what, and then when they told when I kind of caught on then, when they knew that I was high or low, but I just stick my hand up and it was, yes you can go if you need to
		461-572	teachers see it as [pause] ummm, it is kind of hard to know. But I do know that they - most teachers are quite supportive about it, now. They'll understand what - umm, I'm trying to get my head around it. They'll kind of understand what's wrong. [yeah] And like, you know what to do. And like you're in control but other times they don't.[mmm] [pause] And it can get really confusing because they don't know what's happening. And urgh, sorry my train of thought [that's okay], they don't know what's happening, and they kind of pin it on the wrong person. You know, they'll pin on me, or pin it on like one of my friends even though they were just getting involved to try and help me.
	Emily	775	What do they say in teacher meetings? [grown ups laugh]
	Morgan	232-233	Uhhh, he [pause] knew someone who had [condition], so he knew what it was sort of like so... [inaudiable conversation with mum] Yeah.
		344-346	sometimes I wouldn't get the work from them [okay]. But was still sometimes expected to have done - it was slightly confusing.
Perceptions of the child	Joe	27-29	So, generally, if I was to walk into a class and I wasn't feeling right, I would just walk out straight away, but if it happens mid lesson. I kind of don't realise it until it's really bad. And so, I'm just clumsily like writing over with my pen not paying attention in class, and yeah, I don't notice it.
		322-326	And most of them are okay with that there's a fair few that were a bit sceptical so they said, go to ummm, the medical bay, which, for me, in most classes was on the other side the school. [mmm] So they'll usually just get a friend to uhh, walk me over there, which was okay
		496-497	

		561-572	umm, not really because they didn't see it as I did. They just saw it as like a little bit of joke and game teachers see it as [pause] ummm, it is kind of hard to know. But I do know that they - most teachers are quite supportive about it, now. They'll understand what - umm, I'm trying to get my head around it. They'll kind of understand what's wrong. [yeah] And like, you know what to do. And like you're in control but other times they don't.[mmm] [pause] And it can get really confusing because they don't know what's happening. And urgh, sorry my train of thought [that's okay], they don't know what's happening, and they kind of pin it on the wrong person. You know, they'll pin on me, or pin it on like one of my friends even though they were just getting involved to try and help me.
	Emily	766	Hmm, probably quiet.
	Morgan	822 832-833	They'd say who's [child] I think they'd say I’m capable, they gave me good grades [inaudible argument with parent]
Expectations	Joe	296-300 365-368 402-408	Yeah, so in the medical bay, they, umm [pause] they keep they let me be independent with it but then also check up on it as well, so they would ask, what's the insulin. Is that right, do, ummm, is your blood sugar okay, is it a range, all that stuff, while also letting me do everything. So letting me finger prick letting me tell them letting me put in my carbohydrates and insulin. It was very good Yeah, I'm kind of, I'm still a little bit sceptical, but I feel that if I tell them what's going on if I try and, ummm, like correct them if they're wrong, then they'll kind of understand [mmmm], and they'll know that what to do next time. . So, like back on the first day, I think, what would be best is for them to just come over to me explain what's happened and run me through what needs to happen because, although I'm quite good at my subjects, I'm not confident that I am, umm, especially stuff like English because my

			spelling ability, and punctuation isn't very easy for me. Compared to, like, normal kids in the class. So, like having a teacher just come over in general and tell me how to work it out and then also, kind of, let me do it myself, really helps.
	Emily	306-310	Well, um, sometimes I just wouldn't get the stuff that other people got because of my [condition] and they still kind of do it, but just differently in this school because they give out E praise points if you attend for the whole of the week.
	Morgan	186-187 344-346 375-379	I was doing uhhh, school when I could, but then I would crash when I came home, that's what happened. sometimes I wouldn't get the work from them [okay]. But was still sometimes expected to have done - it was slightly confusing. **Parent** So I think he probably puts under stress on to yourself, didn't you? **Child** probably, yeah
The impact on the Child			
The loss of experiences	Joe	160-164	Well, I know this one person didn't want to be around me because they thought they would have extra responsibility [pause] as a friend, er, but usually it just affects it because they, I usually go off to do my bloods. I come back, I've missed quite a crucial part of like the conversation I don't know what's happening. So I just stand there, go along with it.
	Emily	208-210 635-636	And they didn't, they rewarded us with parties if you attended enough, but we never really attended enough because of me. I would like more food tech cuz I haven't got it yet. I've been in the school for two years.

	Morgan	428 622-625 728-741	Missed it when the cricket started, not so much athletics though So are you thinking about in terms of missing out things in school? **Child** 25:36 Yeah, ummm [long pause]. **Child** 29:57 Well no, they didn't have it in the end **Parent** 29:59 No cos lockdown meant they didn't actually go did they? **Child** 30:01 Yeah. **Rachel Jones** 30:03 I guess how, how do you feel about, you know, not having been able to go on those trips and things like that? **Child** 30:09 Alright
The emotional roller-coaster	Joe	16-21 239-244	Sometimes I get frustrated as I say, And sometimes I forget. And I think it's just like the [CONDITION] talking, but I just stop. And I can't think straight. And so sometimes I don't treat myself properly. And it can all go topsy turvy especially at school, it can really affect like my mood and how I'm working. I mean yeah, because that ki, kind of stuff, even if it's not purpose, it builds character. It can really shape someone to be a better person and be more understanding. And I feel like that's what's

			happened to me, [mmm] but I feel like i'm a bit older and more intelligent, then some of my friends in like the real world, not just academically just in general.
	Emily	323-328	Well I don't really think about it at the time. But if the teacher mentions that we didn't get the points then I kind of feel like it's my fault. [You say that you feel like it's your fault, does that make you feel worried or sad or something else.] Well, if people mention it, it kind of makes me feel sad. But it's not really my fault because I do have [condition], so it's just my body.
	Morgan	428	Missed it when the cricket started, not so much athletics though
This is my reality	Joe	179-184 207-208 384-387	um, I feel comfortable just scanning [mmm] and, but I kind of get hesitant at finger pricking and stuff in front of someone, or if they come to the um, place where I do it because I don't know how they will react to it because I know some people are, are squeamish, some people just don't like needles. And so I kind of try and avoid it at most parts, but sometimes I can't, and I just hope for the best that they weren't really mind. So, like I kind of had to just break it to them, like slowly, and that. I'd also want them to know that going out is just normal thing for me. [Yeah] And that, um, if I, if something happens, bad, then they shouldn't freak out and they should just tell me to go somewhere with someone. [mmm]. I'd feel like that'd be the best possible solution.
	Emily	26-28 64-75	Yeah, yeah. So, with my [condition], sometimes I have [medical event], and with the [condition], sometimes gives me mouth ulcers. **Rachel Jones** 02:22 [long pause] Do you ever know that they coming, or is it a bit of a surprise. **Child** 02:28 Uhhhh, I don't really know when they're coming. **Rachel Jones** 02:32

			Okay. **Child** 02:34 They just happen
		101-102	I don't really know, i'm not so tired afterwards, I don't really pay attention.
		327-328	But it's not really my fault because I do have [condition], so it's just my body.
	Morgan	77-79	Just stay in my room, in my bed most day, just getting up to go the toilet, and eat.
		55-58	So a good day, now would be ahhh, sort of normal, because I've gotten better at managing it. I'd be able to go to school and uuuh, the weekends, play some games and watch some videos and stuff.
		89-90	fairly good. Just, um, I caught a cold and I've just had a bit of a bad style recently.
Wanting to be normal	Joe	60-66	Yeah, most of the time, my scanner will do the work, although sometimes if I'm low, and it tells me that I'm low, sometimes I'll just try and like skip it, so I don't interrupt the class. Like, I won't scan because I'm kinda in that mental state already and I don't... want... to. But then usually, ummm, like this girl in front of me, her brother's [condition], so she will tell me, did you scan, even though we don't really talk much. Like she'll kind of just turn around and be like was that your scanner, have you scanned, if I haven't gone.
		120-125	But, like if it's midday then. And I'm like, in lesson, I don't really want to interfere. And sometimes I do know that, and yet, I don't think about what might happen if I don't so I've just turned off, ummm, until I actually feel it. And then when I do I scan and go
		135-137	

		150-152	I don't want, errrm everyone to look at me, because that just gets really awkward and I don't like them kind of situations at all. I kinda like to just to blend in with the class, not be that one kid that always stands out. I kind of don't want everyone to know that I'm different because it can affect friendship groups and how people look at me
	Emily	662	Well, I think I just want to do it.
	Morgan	186-187 282 436	I was doing uhhh, school when I could, but then I would crash when I came home, that's what happened. Hmm, i did less, yeah. Not really. Sometimes when we played, but... that was rare
The role of peers			
Friendships	Joe	9-10 160-164 451-461	And uh, usually I'm okay, got a lot of support with family and friends, So, it could be a lot worse. Well, I know this one person didn't want to be around me because they thought they would have extra responsibility [pause] as a friend, er, but usually it just affects it because they, I usually go off to do my bloods. I come back, I've missed quite a crucial part of like the conversation I don't know what's happening. So I just stand there, go along with it. Okay, um, well, my friends see me just as a normal kid who sometimes needs to distance himself for whatever reason, [mmm]. and err, just other kids. Ummm, like, I don't really want to tell them too much about it because it's not really for them to know and also it's, it can cause a lot of umm, questions. Like a lot of them have heard of type two [condition] but not type one, so I did suffer a little bit of that, like, saying, oh why do you have fat and carbohydrate, shouldn't you be off that and all that stuff, and umm, that kind of upset me quite a lot, [mmm] but it wasn't too big of a deal, because I knew what they meant. Most of the time it was out of curiosity, trying to find out

			what it was. But some - two people knew what it was because I told them, but still did it, [yeah] which is never really nice.
	Emily	206-208	Well, I didn't have too many friends in my last school because I had a friend that wouldn't let me play with my other ones
	Morgan	631-637	friends. Ummm, Sometimes I would have felt uhhh, excluded from the friend group. Because where I missed up, I missed uhhh, inside jokes and stuff like that. And uhhh, outside of school, I wouldn't normally get to uhh, go out into town with them. And eventually, they just stopped inviting me. Because they knew that I would say no. And not felt a bit bad when I started to get bit better, and could have gone, gone out into town with them.
Peer perceptions	Joe	64-68 73-79 208-212 336-321	But then usually, ummm, like this girl in front of me, her brother's [condition], so she will tell me, did you scan, even though we don't really talk much. Like she'll kind of just turn around and be like was that your scanner, have you scanned, if I haven't gone. Yeah, a lot of people in my class are kind - except this one kid called [child name] he hates work, And so he always tries to get out of it by going to the office saying that he needs to fill up his water. And then I just go off because my blood sugar's are high or low. and he's like, what is he doing, [mmmm] why does he get to go [shouting] and my teacher is just like, he's got a medical condition, you're just lazy. And so with all this new attention it kind of annoyed some of the classmates that they - I was now, like being mentioned a bit more in class because all this new stuff had happened. [mmm] And that kind of led to, like teasing, them bullying, all that stuff But I didn't actually know anyone there, so I just said to next, person next to me. Will you go over to medical bay with me, blah blah blah. It was in English, and they turned out to be quite to be quite nice to me. Probably one of the only ones that have talked to me during like lunch and break, because I kind of told them everything that was going wrong. [Yeah] and that was good, so that really helped
	Emily	236-237	Well I don't really mention too much about my [condition] to my friends.

		292	I think they treat me, just the same as everyone else
	Morgan	654 842	I still felt included when I was in school. I don’t know [groans]
What is helpful?			
Covid & Home learning	Joe	458-462 469-474	Yeah. Pandemic for me was really good because I didn't have all the stresses of school, like getting there on time and stuff, but I'd still have to wake up, which sucks [laughter]. But I'd also have the reassurance of being at home already. So it wouldn't be calling home if I was, my blood glucose, like ketones were really high, I'll still be there so be a lot easier to access my SOS and know what to do.[mmm] In general I prefer being in school. So I get to actually see my friends in real life and learning is a lot easier, I'd say, long term in school. Because in short, like short term, it's harder to be in school than it is online, but after a while online, you kind of jump back to Lessons previously. Ummm, and then you quickly go back to a lesson before that, but then you start a completely new topic.
	Emily	472-474 504-507 515-516	Well, at one point we did our lessons at home. And that was, um, good cuz normally uh, school and three o'clock and when we were at home it only ended at lunchtime. [Okay, so it's a shorter day]. Yeah I think it would have been nice to be in school at that time but I'm not sure if that will be better. I think it will be the same. [mum laughs in the background] ummm, you can go backwards and forwards between slides. And then you know what you need to do.

	Morgan	477-480	when it transitioned to online lessons with actual video from teachers. Uh It was, uh, probably the best school's being since probably primary school. So I've been able to do other things as well.
		773-788	if you'd been able to do things online, from year seven, and when you needed to, do you think that would have changed things for you? **Child** 31:31 I'm not sure **Rachel Jones** 31:36 It's an abstract question, isn't it? Because you haven't actually experienced that. But yeah. **Parent** 31:41 but you, you said to me, if I had been able to sort of know that the COVID was going on, and I had to do them online, I would have kept at least one of my other GCSEs **Child** 31:51 DT
		929	Or half and half, like I did at the end of last year.
Adaptations	Joe	317-319	Well, at first I just had the card that'd flash up. Umm, sometimes I'll have to keep it near for a while for them to actually recognise it. [oh okay] But when they did, I could just go out,
	Emily	424	They sit me near the front.
		515-516	ummm, you can go backwards and forwards between slides. And then you know what you need to do.
		600-602	Well, you're allowed to work with your partner, already. Yeah. [And is that helpful?] Yeah

		712-715	Oh, if you miss a day then you'll have to catch up on the work. [Okay, and you do that at home or would you do it in school?] in school.
		931-933	maybe, make sure they have that thing that you give them when they have had a [medical event].
		946-947	Maybe give them like a diagram to look at when doing something.
	Morgan	115	When I saw a specialist I had uuuh, red, yellow and green activities to help me manage energy levels.
		264-266	Umm yeah, uh, we had uh, the hub which was a uh, quiet place, that I could go to rest, and uh, [long pause] if I was missing a lesson , uh, the, uh, staff there, uh, would go and collect work for me so that I could do it at another time, If I could.
		393-396	Uh, I could, I could go to the hub in assemblies instead of assemblies. And uh, whenever seating plans were made, I'd always be uh, next to a wall. So that noise is only coming from one direction instead of all around me. So that was helpful.
		761	was alright. [laughs] It was alright when I was there.
Hopes for the future			
Transition	Joe	344-350	hmm, quite scared... To be honest, I [drawn out] don't really know how I should feel about it, as I've had bad experiences before, [mmmm] but i'm also quite, um, open about it, like I won't just keep it all bottled up inside because I know that if I tell someone, it's a lot better.. I actually got to go around, talk to the head of the year, who also did all the therapy and stuff for the, um, kids. In that year, And it was actually really good because - and it made me a little more clear about it
		400-403	

		422-427	Probably just follow me up because in hospital work up - even if I’m conscious - work is not easy at all. [No] Especially if I'm feeling really bad. So, like back on the first day, I think, what would be best is for them to just come over to me explain what's happened and run me through what needs to happen Well, it really depends because if I know I'm going to be in hospital for a while. like, I'd rather have, like my phone next to me, so like before and after school hours I can message them see what's happening, see what like I need to catch up on, or what I'm missing, just so I know, [mmmm] instead of coming back and being loaded with all this information
	Emily	840-844 853	I think that opening that clubs. [Okay] And in homework we will be doing something called tessaman. [So a few little differences for you then compared to what you do now. And your, your lesson is going to change at all do you think?] yeah, I think we'll have more of some lessons and less of the others. I'm excited for year 7.
	Morgan	531 561-563 598	They went well until like, I caught a cold. And then I missed two days. So before you umm, I guess started, did you have any meetings with the teachers? [No,no]. They said, wait about two weeks for us to get around. [Yeah].
Thinking long term	Joe	591-603	I feel like it's going to be a lot harder because of, you know, teenagers, new people, them finding out new things, that might have the same like words and stuff but not actually correlating to, if that's the right word, umm but also [pause] I'm quite excited, because there's always new things like, I feel like there's one day going to be a cure for [condition]. Like, if that's like a pancreas transplant, or like artificial like my pump but a lot better [mmmm] and more - that can read my blood sugars and do it without me even needing to. Ummm [pause] and also, I'm quite excited because I really want to be a doctor when I'm older. I really want to study in my area, type one [condition] and [CONDITION] and become specialist in that, and like go around the world, teaching people about it, helping young kids who suffer with what one of these, or both of them. And, yeah, I'm really excited.

	Emily	560	Ummm, i don't know (what whould you like the adults to do differently if anything)
			I don't know. (the future)
		906-907	Well, I'm, I'm hoping not to have a [medical event] at least three years before I am able to drive so then I'm able to drive.
	Morgan	875-882	**Child** 35:11 Not sure. **Rachel Jones** 35:12 Not sure. What job would you like to do? Do you know? **Child** 35:20 something with computers that's what I've always wanted to do

Appendix O – Validity of qualitative research

Yardley's principles of validity	Evidence from current research
Sensitivity of context	- Relevant literature from both inside and outside of educational psychology has been considered. The wider impact on both the family and the child themselves are considered, before a systematic approach is applied to examine specific research in relation to the chronically ill child's experience of education, as well as their caregivers experience. - Relevant research is naturally given in detail in the literature review (part one) but is also considered in the introduction and discussion of part two. - Consideration has been given to ethical issues. Full ethical approval was obtained, as was informed consent (examples of ethical issues considered during the process are evidenced in appendix L, and examples of the consent and information forms are also available in appendix D,E,F & G). Participants were given the option to ask questions prior to, during and following the interview. - The right to withdraw from the study up to two weeks following their interview was explained through written and verbal means. - Participants were given debrief forms with signposts to further support if they felt it was needed following the interview. - The research made every effort to ensure the participants felt as equals in the relationship. Furner discussion of this is evident in part three.
Commitment and Rigour	- Supervision was utilised to help the researcher identify key approaches through a reflexive supervision. - Six interviews were conducted – three with caregivers, and three with young people. - Semi-structured interviews were utilised to give participants the opportunity to tell their story without guidance. The researcher followed a semi-structed interview schedule (evident in appendix H) though allowed the participants to guide the interview as they saw fit, probing further as needed. - The researcher followed suggestions from Smith et al (2009) when analysing their data. - The research followed the emersion processes as suggested by Smith et al (2009). The process used can be seen in appendix K. Examples of the annotated transcripts are evident in appendix P and Q. Fully annotated transcripts have been submitted separately. - A research diary was utilised to capture the thought process of the researcher and the progression of the research (See appendix S for examples of this process).
Transparency and Coherence	- Careful consideration was given to the ontological and epistemological stances before the research question and approach were identified. These stances are explained in part 2 and the decision processes is explained in more detail in part 3. - A clear process was demonstrated when analysing the data as advised by Smith et al (2009), and evidence of this process provided (appendix K) - The researcher acknowledged their own position and the possible influence of this on the research in part two and part three. - Examples of analysed transcripts are included for transparency (Appendix P and Q), with all annotated transcripts submitted separately. - Table 5 and 6 in part two are used to evidence the themes, and the presence of these themes for each participant. - The most meaningful quotes are presented in the body of part two, with full tables of supporting quotes in appendix M and N.

Impact and importance	- The research has yielded important information for educational psychologists to consider in their practice. It is also hoped that this research has given voice to chronically ill children, and the caregivers of chronically ill children. - Future research has been considered and is discussed in part two and part three. - This study was identified following extensive searching of the current literature. Research that looked the views of both the caregiver and the chronically ill child in regard to education was lacking, specifically so in the UK. - This research highlights the importance of a good relationships between home and school when meeting the needs of chronically ill children. It has been suggested that EPs have a role to reflect, reframe and reconstruct with schools, helping the voices of these children and caregivers to be heard. EPs may also be able to offer holistic assessment to aid understanding of the childrens needs. - This research has theoretical generalisability (Smith et al, 2009) and it may allow education settings, families and other professionals to reflect on the needs of the child, and the process through which they engage with each other in order to support the child in education.

Key

Linguistic – italic text
Descriptive – normal text
Conceptual – underlined text

Appendix P – Example of transcript for Sarah (Emily's interview) with exploratory comments and emerging themes

Systemic issues Breakdown in communication Loss of experiences Mum's emotions – difficult/guilt/anger?	[yeah] And for a little while, a little while, she was okay but we started getting them these letters from school about attendance. I've had them before [laughs sarcastically], with the other children. But, umm, you know, saying, 'Oh, it's really low, we're gonna have to speak to umm the governor's and involved county council', umm you know, umm you need to improve your attendance type of thing. So that was year three. She, she went into year four. And [pause, sigh] that was when things totally, really broke down I mean things were already tense with the school with the attendance level. They weren't happy with, but then, um, in year four I became quite unwell, which [child] was really worried about, [mmm] it was hard to get her into school anyway because she was worrying about me. We had to have, ummm, because of my care needs, we had to have the local social services we're dropping them into school - we had like a child services lady coming in, and take them in and that made her different as well, [mmm] I think that made it harder for her to make friends. The school did try, i can't remember what they were called, forest school lessons or something to try and encourage some friendship but it didn't really help. [Child] was getting really upset about thing's like she was going in, and she'd have missed one part of a lesson. So, I don't know, [stumbles over words] in whatever they were doing. And then the next bit would be something fun like making a mask or doing, ummm, one of them was a food thing, and they were saying oh you can't do it because you haven't done [pause] the paperwork beforehand, you know like the school bit. And um, then she would say, well - but they weren't sending it home, you know? and uh, all throughout primary school, they didn't send work for her to do, you know, other than what they were set in school, and ur, the standard homework. If she was off, she was off, there was nothing, there was no homework coming back, there was [pause] nothing. So it was, you'd lose complete track of what was going on in school unless I asked my mum friends and found out from them what they were doing. It was [pause]	*The laughter indicates mum can't believe they're sending these letters to her, when they're aware of the YP's needs – almost as if to say there is nothing I can do. Lots of umming - as if mum is trying to find the right words to explain the impact of the letters.* *Totally, really – to indicate the severity of the situation to me?* Mum's emotions are clear here – she feels guilty for the impact her health is having on the YP. Frustration – they weren't sending it home. Mum doesn't want her to miss out, school aren't working with mum. Almost a punishment of the YP – you can't do the nice things without the academics. Almost like the young person is pushed out, socially, emotionally, academically.

Advocating for the YP. Not our problem / blockers? Lack of knowledge/collaboration Judgement from school Mum validated/ guilty	that was really hard, and then due to something happened with [older child] we - with safety concerns - we removed them from the school. The relationship between us and them, had just completely broken down. Um, [child] was so unhappy she was coming home in tears every day and I was sending emails every day saying she's not making friends, she's not, you know you need to be supporting her when she is there, and they're saying, well, she's not coming enough and I'm like well because she's anxious and I couldn't force her in when she was crying and stuff about it and that that can be a trigger for [medical event] anyway, so it was all becoming like a vicious circle of she'd get anxious then she said have a [medical event], then she couldn't go in anyway, [sad laugher] it was just a disaster. Um, so that was, that was about when we stopped, because it's not always when she's -most of the time if she'd had a [medical event] she'd be fine to stay in school, if she was having them in the night, then she would be too tired to go in, or sometimes they'd make her feel really sick and they just didn't seem to get that it's more than just the actual [medical event] that affects you. It can be your muscles aching and all that sort of stuff, and [child] was having more and more weird problems that we put down to seiz - we always were told they were [condition] related so things like muscle aching, um, the stomach pains that she would get loads of mouth ulcers, which we thought were where she was biting your mouth. um, and er, it was only by chance, one of my friends said to me, 'Could she have what you got?' because I, I have a condition that causes mouth uclers, and problems with joints and stuff. I've got something called [condition]. And it's really rare in, in our sort of um, ethnicity. So, and it's not a genetic disease and - it can be familial, I think it's what they call it when it can run, but it's not actually like handed down. I don't know, I know that it's not actually handed down like like [older childs is] [mmmm]. So they, they, we eventually managed to get her tested and she has got the [condition] so that would explain all the things that we were seeing. So we were keeping her off for, that they were	The suggestion that school can only help if she is in – but the young person can't attend due to her medical needs – punishing her for not being 'healthy or normal?' washing their hands of their responsibility for YP. Emotional stress of everything is triggering medical condition. Lack of understanding and knowledge from school due to their experiences. YP diagnosed with a second medical condition

Breakdown of relationships Communication and collaboration Communication, empathy Punishment for being ill?	saying was anxiety, they were actually real, they weren't in her head. So that was good, in the way that it made me feel validated I always knew I wasn't keeping her off for no reason [yeah]. But that I think the school treated me as if though I was. So yeah that was, that was that was leaving [name] primary school so she was in a primary setting, she would have gone on up and left in year six, [yeah] at that point we've moved her to [middle school], which is a school about three miles away, we'd removed her because of the uh, safety concerns so we were, I'd actually deregistered them so technically I home educated for a couple of weeks, but we, it was just before the six weeks holidays, and the local authority were happy for me to just say, fill in the forms and say I was doing it and they didn't come out and check or anything they said it was fine because she was registered to start in September, at [middle school] So she went into year five, which is really good because actually, that's when that school does an intake. [Okay] so just happen to fit in really well, that she wasn't going to be the only one joining that, year, if that makes sense. [Yeah]. She was really, really, really nervous about going, so I spoke to them at length beforehand about all the problems we've had with attendance and um, making friends and um, one of them suggested we try and go on the parent support group for the school, and introduce ourselves and see if anyone wants to meet in the holidays, which we did and we met a few parents beforehand with little children that came around to play with her so she knew some people before she went in and I think that was really good advice. That really helped. And they said that if she was at home they would make sure that work came home, and that it was linked to what's happening in class, so we kind of headed off a lot of the problems we've had before, before we started [pause. mmm] and it's gone really really well with that school, aside from, we have had the generic letters about attendance [laughs]. They say, they always phoned me and they say we're really sorry but she's got to bring a letter home or we're emailing your letter. Please don't worry about it	*They weren't all in her head – implies that school thought that they were making up these issues?* Lack of trust from home/school to the other. Mum doesn't trust school to keep YP safe, school don't believe mum. *Made me feel validated – mum started to doubt herself and her ability as a mum?* Reached a point where it was untenable. YP removed. Safety concerns related to older brother. Anxiety around starting the new school, anxious that history will repeat itself and mum & YP will have same experience? School appear to be on the ball, recognise and hear mum and offer solutions? Socialisation and friendship again key aspect. Appear to want to work collaboratively with mum?

Healthy people in the YP world Lack of recognition for achievements Positive adaptations – going above and beyond? Facilitating socialisation and learning Impact of covid/home learning Health impact	you know we have to generate it so they, they kind of take that, that view which is really helpful. Um, the, the, yeah, I, the only thing they still have the stupid rewarding attendance thing [mmm] it's slightly different there, but they have the full attendance, and you get E praise points. So for every week that you're in for full attendance, you get 100 E praise points which is quite a lot. And [pause, voice breaks] she hardly ever gets them because she's not, you know, [mm, incoherent words] and then that really upsets her because she really works to those. Um, In fact, she rarely got much sort of, ummm, sort of, well done, praise and stuff but since the lockdown learning that's been different, because suddenly she's getting letters like, um, saying that you're one of our, our work heroes and you're trying your best and suddenly we're getting, you know, brilliant engagement, top learner, all this stuff which we never have before. So that was really lovely but it's sad that it's taken them actually all being off for them to recognise that she does work really hard. [Yeah] um, [pause] because we were doing it before, but weren't recognised for it but suddenly when everyone was like oh yeah you're doing really, really well, well done. They had to shield, a lot longer than the other kids who went back, um, and I found that a bit hard that they didn't, they uh at start, to start with, they just, were giving them the online learning, but all the videos stopped. So I said to them, you know they're missing their classrooms, and I have to say the school were amazing. They, um, made it so that they could [pause] be live in the lesson so the teacher had them, like a computer on the desk, and so they could be part of the lesson. um, but the rule was, I couldn't be present at all for any of those video calls because that was safeguarding those children in the, you know, so that was fine, um. So yeah, that, that was really lovely because they, their friends knew they were there and they could interact and that worked really really well. So on that side of things. That was really good. I think [childs] attendance at the moment is like, 86.2, I think at the minute, which is pretty good, for [child]. Um, I	*Stupid rewarding attendance thing – frustrated that school still award ‘wellness’.* *Pauses – it's emotional.* YP is continuously being punished for something beyond her control. Why is a YP value measured by their health? It has taken everyone experiencing what the YP goes through for them to recognise her qualities. *Pauses to reflect, ‘sad.’* Again, takes the ‘well’ children experiencing it for YP resilience and resolve to be recognised. When it returned to normal, shielding children were just forgotten – if I worked before why stop it when they can meet their needs? Adaptation to continue online lives. *Really, really well – emphasis on how well things worked, and how the school adapted to supporting the children and young people.*

Key

Linguistic – italic text
Descriptive – normal text
Conceptual – underlined text

Appendix Q – Example of transcript for Joe, with exploratory comments and emerging themes

Sadness/anger Breakdown of trust/relationships YP perception of others Shock, sadness	this new attention it kind of annoyed some of the classmates that they - I was now, like being mentioned a bit more in class because all this new stuff had happened. [mmm] And that kind of led to, like teasing, them bullying, all that stuff and thats... and then also with the teachers and the needles... Umm. It was, I feel like it was forced, and I did not like it at all. And so, after a long time... They, I left because they, because after that incident with the needles and after that, I went in for another one day to, to see what would happen. And, yeah, they made me prick my finger a lot, and they also said that the teacher that was going to supervise me at PGL, which is where we were going for like the end of the year, wouldn't anymore. [Okay] like, they just would not look after me. Even though, just because they got in trouble for what they did. And that, um, really annoyed me because I thought that we were good, with each other... because she was actually a quite a nice person. She just didn't learn and then she obviously got in trouble, a little bit, and then took it out on me in a way. And so, I've never seen her since. I hope she's okay and everything but it really hit hard, and I kind of lost my trust, in people. [stumbles over words] I kind of got close to especially adults. Cos it shocked me that they would like try and lie [oh go on, child]. Try and lie about like not doing something that and trying to get me in trouble for it [mmm] it got... quite bad in that situation. So, I just didn't think that it could turn out that way. Really, **Rachel Jones** 14:19 thank you for sharing that with me because I can imagine that that was a really horrible situation for you to be in, you know, and listening to sort of mom telling me about it and now you're telling me about it. You know, I feel very sorry that you had to go through that and I think it's very kind of you to hope that that teachers still doing well, and still showing kindness, **Child** 14:40	YP felt discriminated against due to their needs – almost like people didn't like the attention he was having *Selective with how he is sharing information, pausing to try and be objective?* Missing out on end of year experiences because of staff member actions – sadness and anger. *I thought that we were good, with each other* – trust has gone here. Sadness and loss? Almost burst the bubble of the YP – realised that not everyone has best interests at heart? *Stumbling over words, pausing – emotive.* Loss, sadness. Shock.

Attitude to life Wanting to fit in Communication Breakdown and relationships Trust and building relationships	I mean yeah, because that ki, kind of stuff, even if it's not purpose, it builds character. It can really shape someone to be a better person and be more understanding. And I feel like that's what's happened to me, [mmm] but I feel like i'm a bit older and more intelligent, then some of my friends in like the real world, not just academically just in general. **Rachel Jones** 15:11 You mentioned when you were talking about losing your trust in people, especially the adults around you, ummm Can you tell me a little bit more about that. **Child** 15:22 Well, so, when I went into year seven I was quite sceptical after that. So I never really wanted to interact with any of the teachers, so I kind of laid back, which worked until I really stood out because of, you know, putting my hand up trying to go out and then doing my bloods where I wasn't supposed to on all of that stuff. And then I got in trouble for it and I., that's kinda the breaking point where I just didn't want to speak to any adults I didn't really know and trust. [mmm] So it took a long time after that, like, after I came out of that school and after the therapist, who didn't really help too much for me. Ummm, because, uhhh [pause] I can't remember. It took a while to rebuild that but then I went to [school], and they were a lot more understanding. I think there's that sort of stuff like might have happened there before, but they kind of, it was as if they were at school for a bit as well. Learning about my, uh the disabilities, and about how to notice it. And now, I'm fairly good friends with them. like i said, I trust them **Rachel Jones** 16:45 That's, really good. I'm really glad that I can hear that, and I think from what you're saying it sounds like it was really important to you that they took the time to learn about your needs and how they could support you, and you sort of said that [school] is been much	Even with traumatic events, YP looks to the positives of them. Forced them to grow up sooner? Tries to blend in with peers, scared of standing out following the previous events? If I blend in, I can't be judged or mistreated? *And then I got in trouble for it* – no plan in place for treatment, so when he did it in class, they punished him for it. The new school had to really work with him to build his trust, and the relationships. Key.

Alive vs living.	better and like you trust people there now and you've got, you know you've built that relationship with them. And I'm wondering if you could tell me a little bit about what that what it was like [school] did that you thought was really helpful for you.	
A life outside of academics The child then the illness Trust and communication	**Child** 17:14 Um, well, so the very first day, there was two kids that they sent with the teacher to walk me around and they introduced me to the class. And I kind of hung around them for a while, not trying to speak to anyone else. And the teacher, my teacher was a science teacher, so he had a little bit of experience in the [condition] field. [mmhm] And so he knew a lot, and he, umm, with like the people in the medical bay helped umm, like, it was more of an observation thing, because I didn't tell them everything as I didn't notice a lot of the stuff that was going on. So with the first about month or two. It was more just them watching me, learning about my, my, learn about what triggered it, what might be happening and it's a lot better because they didn't tell me that they were doing this, and so I didn't really like get scared that they would, you know, blurt it all out and what, and then when they told when I kind of caught on then, when they knew that I was high or low, but I just stick my hand up and it was, yes you can go if you need to.	Focus from school not just on the academics, but the social side of things, and a teacher who understood and could build that relationship. Took the time to get to know YP as them, not as a [condition] only. Relationships, trust and understanding appear to be key for YP. YP appears to find it easier when he isn't judged or questioned, just 'yes off you go' as they know. Communication across staff is key.
	Rachel Jones 18:36 So it sounds like I[school] umm, were a lot more flexible in meeting your needs, and it also sounds like they took the time to really understand what it was that got your bloods high or what got them low so that they could sort of pick up on it a little bit for you as well.	
Trust in the young person – allowing them to spread their wings	**Child** 18:54 Yeah, so in the medical bay, they, umm [pause] they keep they let me be independent with it but then also check up on it as well, so they would ask, what's the [condition]. Is that right, do, ummm, is your [levels] okay, is it a range, all that stuff, while also letting me	

	do everything. So letting me finger prick letting me tell them letting me put in my [levels]. It was very good.	Caring, but giving YP autonomy – almost as if he feels seen.
	Rachel Jones 19:25 it sounds like that was a really good balance between letting you be a bit of a grown up about it and take responsibility for it but also just checking in and making sure that everything was right, and that you haven't missed anything so I guess it was a good way of building that [recording cut out] wasn't it.	
	Child 19:44 Yeah.	
	Rachel Jones 19:46 Okay. Um, and when you moved up to secondary school then, and, and you had to go to all the different lessons and you have all different teachers. Ummm, how did you find maybe having to let all the teachers know that you need to maybe check your sugar's or did an adult, do that for you.	
Adaptations Barriers Communication Lack of knowledge/understanding	**Child** 20:09 Well, at first I just had the card that'd flash up. Umm, sometimes I'll have to keep it near for a while for them to actually recognise it. [oh okay] But when they did, I could just go out, but after a while it kind of got broken down, then I lost it, but I didn't know where to go to get another one. So I kind of just put my hand up said, like, through every teacher that blah blah blah, I have to go outside and check my blood. And most of them are okay with that there's a fair few that were a bit sceptical so they said, go to ummm, the medical bay, which, for me, in most classes was on the other side the school. [mmm] So they'll usually just get a friend to uhh, walk me over there, which was okay. But I didn't actually know anyone there, so I just said to next, person next to me. Will you go over to medical bay with me, blah blah blah. It was in English, and they turned out to be quite to be quite nice to me.	Card – does this draw more attention, or does it leave YP without. Support for longer, waiting for them to notice it? No clear plan for who he speaks to for support/a replacement card. *Sceptical – implies lack of shared information, staff weren't aware of this need.*

Appendix R – Superordinate and subordinate themes for all participants with emerging themes noted

Themes for Joe				
The adults around the child	The impact on the child	The role of peers	What is helpful?	Hopes for the future
Relationships with staff - Collaborating with staff - Trusting the adults - Communicating - Breakdown and relationships **Perceptions of the child** - Judgement - Lack of understanding **Staff knowledge** - Lack of knowledge - Development of knowledge - Having to upskill others **Expectations** - Understanding of medical need - Engagement in learning	**The loss of experiences** - Keeping myself at a distance **The emotional roller-coaster** - Embarrassment - Shock, anger - Sadness **This is my reality** - Managing the medical need **Wanting to be normal** - Wanting to blend in - Wanting to fit in	**Friendships** - Socialisation - Fear of friendships **Peer perceptions** - Judgement - Perceptions of others	**Adaptations in school** - Lack of understanding - Being a burden **Covid & online learning** - Positives of online learning - Impact of covid on health	**Transition** - Move to new school **Thinking long term** - The future of school - Spreading my wings

Themes for Emily				
The adults around the child	The impact on the child	The role of peers	What is helpful?	Hopes for the future
Relationships with staff - Relationships with teachers - Trusting of teachers **Perceptions of the child** - Staff views **Staff knowledge** - Sharing her needs **Expectations** - Academic	**The loss of experiences** - Not being able to do food tec/swimming **The emotional roller-coaster** - Hard to predict - Punishments - Reminder of being different **This is my reality** - This is my life - Matter of fact **Wanting to be normal** - Exclusion from lessons	**Friendships** - Socialisation **Peer perceptions** - Peer experiences - Peers vs me	**Adaptations in school** - Interventions - ‘sat at the front’ **Covid & online learning** - Striking a balance - The positives of online	**Transition** - Excitement – doesn’t see herself as sick **Thinking long term** - ‘I don’t know’ - Optimistic

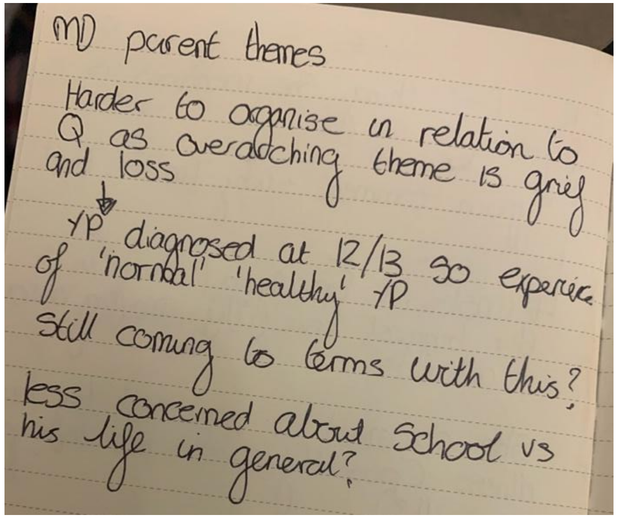
Themes for Morgan				
The adults around the child	The impact on the child	The role of peers	What is helpful?	Hopes for the future
Relationships with staff - Communication **Perceptions of the child** - Perceptions **Staff knowledge** - Their personal experiences **Expectations?** - ‘They expected me to have done it, which was confusing’	**The loss of experiences** - Academic potential **The emotional roller-coaster** - Emotional impact – difficulty articulating **This is my reality** - Alive vs living **Wanting to be normal** - Blending in with peers	**Friendships** - Socialisation - Trying to join in **Peer perceptions** - Impact of others choices - Perception of others	**Adaptations in school** - Changes to timetable **Covid & online learning** - Blended learning	**Transition** - School to college **Thinking long term** - Looking to the future

Ian and Sophies themes					
Collaborating with school	Hopes, fears and the future	The perceived impact on the child.	School isn’t for chronically ill children	Despite everything…	The emotional impact
Relationships with staff - Point of contact/a relationship with someone - Collaboration **Staff knowledge & perceptions** - Lack of knowledge = lack of adaptations - Knowledgeable other	**Into the unknown** - What if? - Afraid of the future **Thriving not surviving** - Things are looking up?	**Sense of belonging** - Fitting in - Missing normal teenage experiences **Friendships** - Losing friendships **Self-esteem** - Impact on self esteem **Academic achievement** - Academic vs enjoyment	**The battles** - Previous battles - Homes vs school **Systemic issues** - Barriers to change - Lack of support **Being left out** - Loss of experiences **The punishments**	**Home Learning** - Impact of online learning **Rewards and recognition** - Achievement recognition **Adaptations** - Simple changes = a world of difference	**Emotions** - The cycle of grief **Being an advocate** - Getting things done **Am I doing the right thing?** - Loss of teenage normality - Limiting expectations

Sarah (Joe’s interview) themes					
Collaborating with school	Hopes, fears and the future	The perceived impact on the child.	School isn’t for chronically ill children	Despite everything…	The emotional impact
Relationships with staff - Communication & collaboration - Lack of trust **Staff knowledge & perceptions** - Lack of understanding - A sick child in a healthy school	**Into the unknown** - Moving schools again **Thriving not surviving** - What if? - Hope for the future	**Sense of belonging** - Letting the child join in **Friendships** - Supportive peers - Relationship **Self-esteem** - The emotional toll on the young person **Academic achievement** - Health vs learning	**The battles** - Barriers to care **Systemic issues** - Systemic rules **Being left out** - Out of sight out of mind **The punishments** - Punished for being ill	**Home Learning** - Impact of blended learning **Rewards and recognition** - Going above and beyond **Adaptations** - Letting him ‘spread his wings’	**Emotions** - The impact on mum **Being an advocate** - it’s your responsibility **Am I doing the right thing?** - Have I done the right thing? - Being the [good] bad guy

Sarah (Emily’s interview) themes					
Collaborating with school	Hopes, fears and the future	The perceived impact on the child.	School isn’t for chronically ill children	Despite everything…	The emotional impact
Relationships with staff - Communication & empathy - Collaborative working **Staff knowledge & perceptions** - Lack of school knowledge	**Into the unknown** - Difficulty in planning for the future **Thriving not surviving**	**Sense of belonging** - Where does she belong? Emotional/social needs **Friendships** - Impact on friendships **Self-esteem** - Comparison to her peers **Academic achievement** - Learning vs living	**The battles** - Barriers to access support - The fight to be heard **Systemic issues** - Who is responsible? **Being left out** - Barriers to lessons **The punishments** - Punished for being ill	**Home Learning** - Impact of blended learning **Rewards and recognition** - Going above and beyond **Adaptations** - Adaptations – seeing the bigger picture	**Emotions** - Feeling judged - Emotional – confidence/anxiety **Being an advocate** - Advocating for the child – giving her independence **Am I doing the right thing?** - How am I being perceived? - What is the right thing for my child?

Appendix S– Excerpts from research diary – reflections on interviews

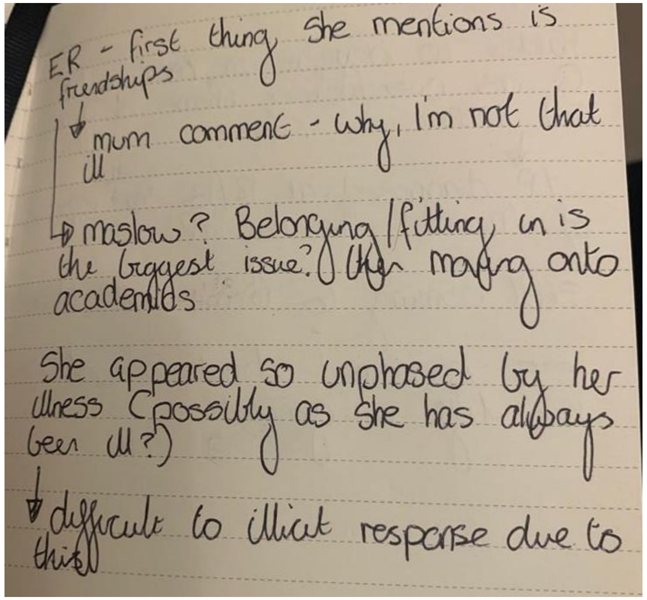


MD parent themes

Harder to organise in relation to Q as overarching theme is grief and loss
↓
YP diagnosed at 12/13 so experience of 'normal' 'healthy' YP

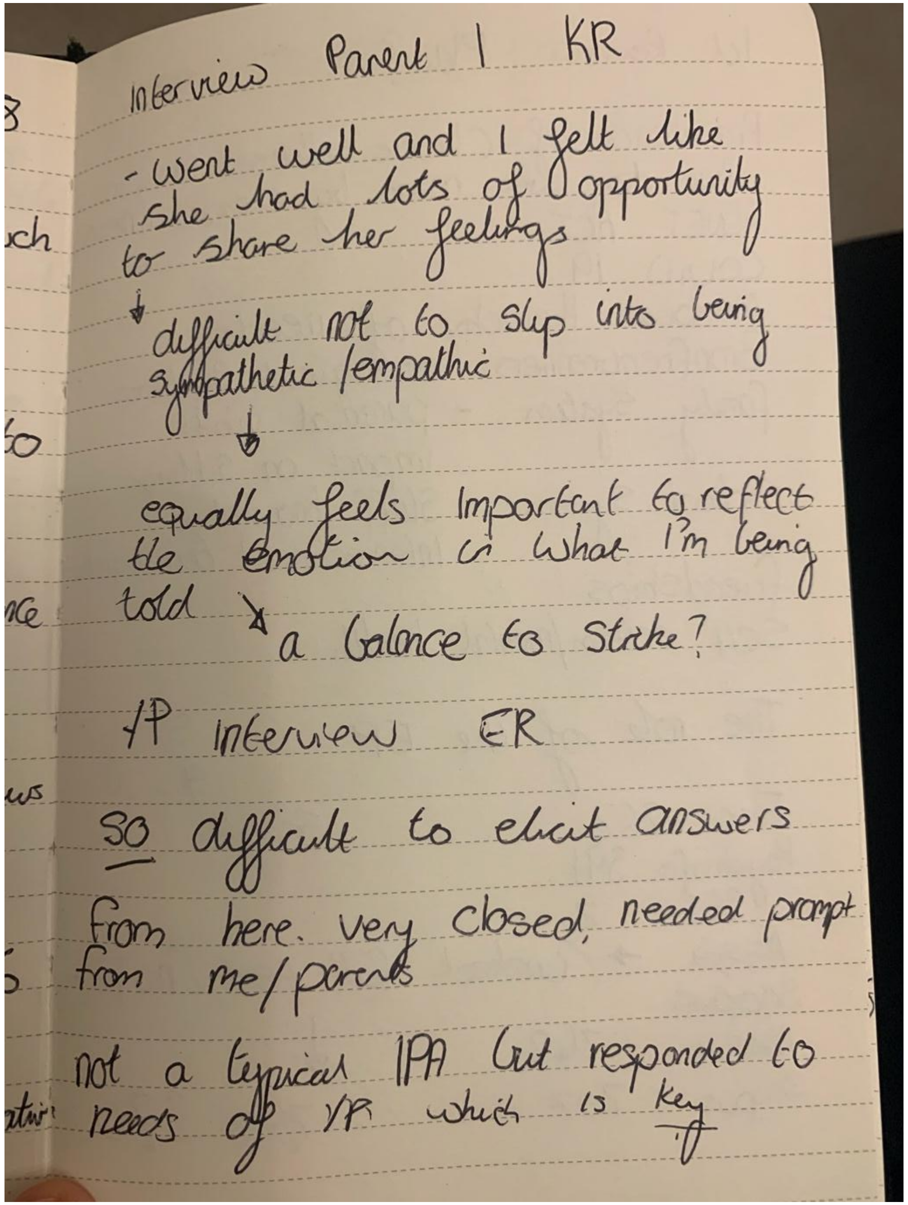
Still coming to terms with this?

less concerned about school vs his life in general?



ER - first thing she mentions is friendships
↓ mum comment - why, I'm not that ill
↳ maslow? Belonging/fitting in is the biggest issue? then moving onto academics

She appeared so unphased by her illness (possibly as she has always been ill?)
↓ difficult to illicit response due to this



Interview Parent 1 KR

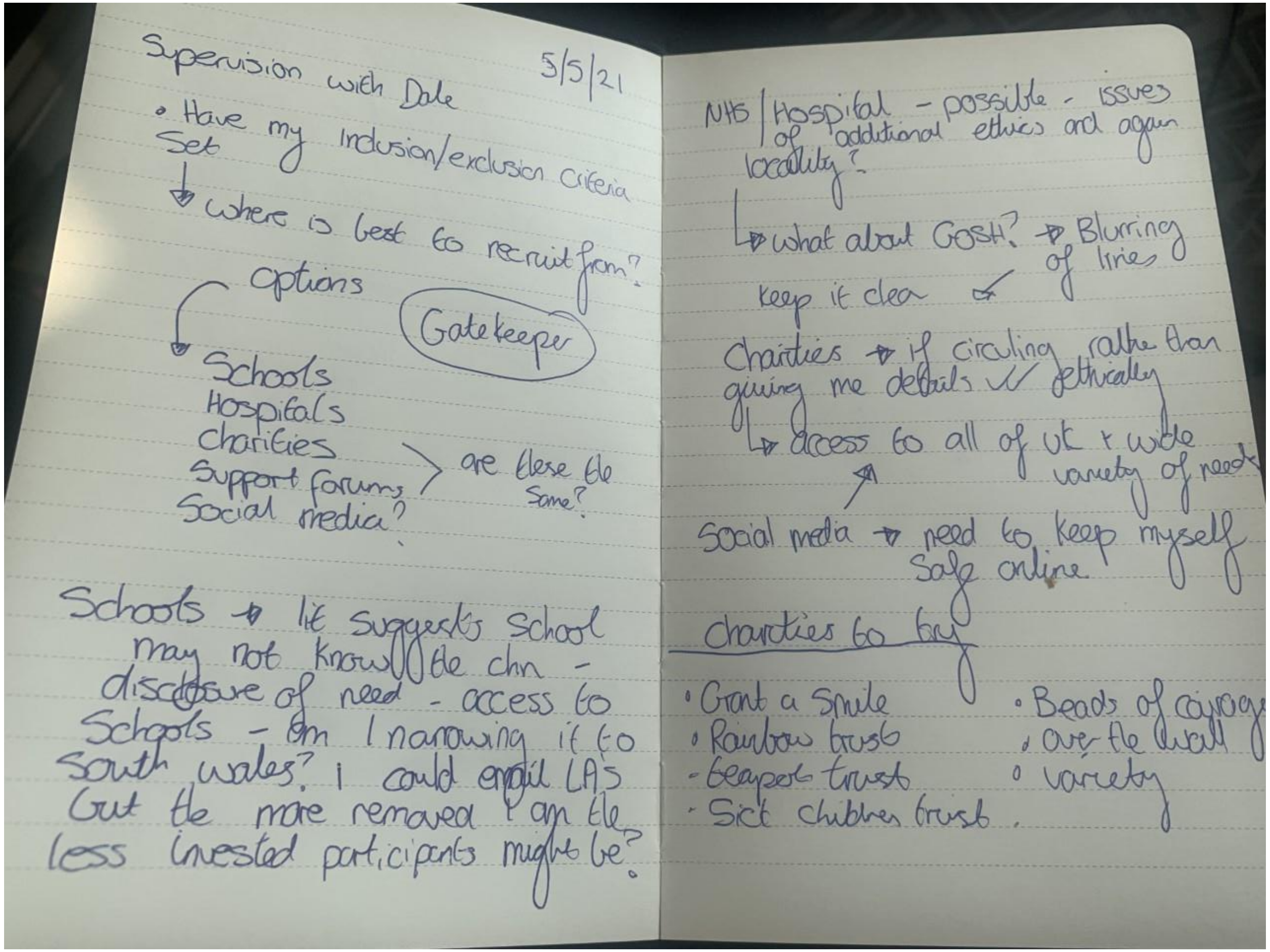
- went well and I felt like she had lots of opportunity to share her feelings
↓
difficult not to slip into being sympathetic/empathic
↓
equally feels important to reflect the emotion in what I'm being told
↘ a balance to strike?

YP interview ER

<u>so</u> difficult to elicit answers from here. very closed, needed prompt from me/parents

not a typical IPA but responded to needs of YP which is key

Appendix T – Excerpts from research diary - recruitment



Supervision with Dale 5/5/21

- Have my inclusion/exclusion criteria set

↓ where is best to recruit from?

options → Gatekeeper

Schools
Hospitals
Charities
Support forums
Social media?

→ are these the same?

Schools → lit suggests school may not know the chn - disclosure of need - access to schools - am I narrowing it to south wales? I could email LA's but the more removed I am the less invested participants might be?

NHS / Hospital - possible - issues of additional ethics and again locality?

→ what about GOSH? → Blurring of lines

keep it clear ✓

Charities → if circulating rather than giving me details ✓✓ ethically

→ access to all of UK + wide variety of needs

Social media → need to keep myself safe online

Charities to try

- Grant a Smile
- Rainbow trust
- Teapot trust
- Sick children trust.
- Beads of courage
- Over the wall
- Variety