# Early Childhood Critical Illness: Exploring the Narratives of Children, Their Parents and School Staff.

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# Abstract

Most children who are admitted to hospital due to critical illness (CI) survive as a result of medical advancements. However, the experience of CI can be traumatic for both the child and their family, as it disrupts family life and there can be ongoing challenges as a result. This research was interested in both how families and children overcome the adversity of CI and how these experiences impact upon and are understood in the school context. Therefore, the current research aimed to provide an in-depth exploration of the stories that young children, their parents and their teachers tell about early childhood CI.

The research included three children, four parents and four teachers. This research was conducted using a social constructivist paradigm with a focus on the stories that were told by participants and how they came to view and understand their experiences. The research adopted a qualitative design and narrative approach. Adult participants took part in unstructured interviews and children were invited to engage in talking, drawing and play activities.

Participants' stories were firstly re-storied to offer rich and detailed insight into their experiences of CI. Then the stories were analysed to identify similarities and differences and several narrative themes and sub-themes were identified. The findings also offer insight into how CI is understood by children, their parents and school staff. The findings illustrate how complex and emotive the CI journey is and how families coped over time in light of family resilience theories. The findings were applied to eco-systemic theory to illustrate how families' experiences are shaped by their interactions with wider systems. Implications for further research and practice are identified.

# Acknowledgments

Firstly, I would like to thank the parents and children who took part in this research. Listening to their stories and all they have overcome has been a privilege. I hope my accounts do them justice.

Thank you to my fellow ‘Cohort 14’ TEPs for keeping me going throughout the ups and downs. I cannot wait to celebrate with you all! A particular thanks to my ‘Cheese, Wine and Cake’ girls, who have got me through.

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Finally to Dinny, for not only proof-reading chapters at 10pm, but constantly believing in me, and being there for both the highs and lows.

This thesis is dedicated to my family, who inspired the project.

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# List of Abbreviations

| | |
|---|---|
| BPS | British Psychological Society |
| CI | Critical Illness |
| EP | Educational Psychology |
| EYS | Early Years |
| HCPC | Health and Care Professionals Council |
| FRF | Family Resilience Framework |
| LA | Local Authority |
| NHS | National Health Service |
| NICE | National Institute of Clinical Excellence |
| PCC | Paediatric Critical Care |
| PICS | Paediatric Intensive Care Society |
| PICS-p | Post Intensive Care Syndrome - Paediatric |
| PICU | Paediatric Intensive Care Unit |
| PTG | Post-Traumatic Growth |
| PTSD | Post-Traumatic Stress Disorder |
| PTSS | Post-Traumatic Stress Symptoms |
| RQ | Research Question |
| TEP | Trainee Educational Psychologist |
| UK | United Kingdom |

# Chapter One: Introduction

## 1.1 Chapter Overview

This chapter outlines the background of the current research topic of childhood critical illness. The chapter will start with providing an overview of the prevalence and context of childhood illness and relevant theory. The chapter will then explore how this topic relates to Educational Psychology practice and provide a description of the researcher's position and motivation. Finally, the chapter will outline the rationale for the current research.

## 1.2 Background and Prevalence

In the UK, thousands of children are admitted to hospital each year and it is estimated that 1 in 1000 will require intensive support in Paediatric Critical Care (PCC) (Paediatric Intensive Care Audit Network, [PICANET], 2022). PCC services provide "care for children with a wide range of conditions who may need a high level of observation or more intensive therapies" (National Health Service [NHS], 2017, p.36). NHS statistics (2017) highlight that PCC admissions are related to a range of diseases and injuries including: respiratory, cardiovascular, neurological and infection. Although some admissions are planned to provide post-operative care for elective surgeries, most admissions are unexpected. For simplicity, Critical Illness (CI) will be used throughout the current research to refer to "children that require, medical, surgical or trauma related care as a result of serious illness or injury" (Paediatric Intensive Care Society [PICS], 2015, p.9).

There are three levels of critical care unit:
- Level 1: Paediatric Critical Care Units: Located in all hospitals.
- Level 2: High Dependency Unit (HDU): May be specialist or Non -specialist.
- Level 3: PICU (Paediatric Intensive Care Units): Patients receive an even higher level of monitoring, increased staff ratio and are often invasively ventilated (NHS, 2017).

There are currently 32 PICUs across the UK and Ireland (Lewis et al., 2020). PICU facilities have developed over the past 30 years and as result of medical improvement, the outcomes of children experiencing life threatening illness has drastically improved.  In 2020, 16,400 children were admitted to PICUs and 96.4% were discharged alive (PICANET, 2022). Therefore, due to the increased survival rates, priority measures are no longer focused on survival, and are instead related to recovery and quality of life (Manning et al., 2018). However, there are a range of potential morbidities associated with surviving paediatric CI (Colville & Pierce, 2012).

## 1.3 Impact of Critical Illness

Depending on the child's condition, their treatment plan may include long-term stays in hospital. Additionally, children treated in PCC can experience a range of adverse and painful procedures and have operations under general anaesthetic (Atkins et al., 2020; Ekim, 2020). Therefore, the experience of being in hospital can not only be traumatic, but they may experience life altering physical and cognitive sequalae (aftereffect of disease, condition or injury) as a result (Abela et al., 2020).

In recent years, the focus has shifted towards the mental health of PCC survivors and their families as CI is extensively reported as a source of psychological distress for the child's family (Abela et al., 2020; Atkins et al., 2012; Foster et al., 2019). Abela et al. (2020) identified a range of psychological stressors for families of children in PCC, including uncertainty about the child's prognosis, changes to the family structure and memories of the time in hospital. It is widely recognised that discharge is not the end of the journey as there are often ongoing complications which arise afterwards (Ekim, 2020).

Manning et al. (2018) developed the Post Intensive Care Syndrome –Paediatrics Framework (PICS-p) to acknowledge the heterogeneity and individual context of childhood. PICS refers to the morbidities experienced by children across their physical, cognitive, emotional and social domains following time in PICU wards. The framework is used in practice to acknowledge that as a result of CI, children will need to recover along these trajectories. The framework recognises that childhood is a time of significant growth.

The framework also acknowledges that a child is uniquely positioned within their family and recognises the potential interdependence between a child and their wider family in terms of their experiences of recovery. The authors recognise that a child and their family members can experience impairment across any four of the domains, but they also interact with each other. Social health is specifically relevant to paediatric populations as CI can impact on both the child and family's social functioning, for example changing work patterns and social isolation. The framework is used as a means of highlighting the areas that support may need to be implemented following a CI.

Research in this field recognises that there is a lack of clear guidance around post-discharge follow up care for families of critically ill children, despite the high prevalence of psychological and emotional distress reported in this population (Colville, 2021). Although some interventions do exist, they are not consistently offered across the UK (Coleville et al., 2012). Similarly, there are clear guidelines for rehabilitation for adults following critical care (National Institute for Health and Care Excellence [NICE], 2009), yet not for children.

### *1.3.1 Post-traumatic Stress Symptoms*

Children and families are at risk of experiencing post-traumatic stress symptoms (PTSS) following their experiences of CI (Colville & Pierce, 2012). However, Kazak et al. (2006) recognise that what causes an event to be experienced as traumatic is to do with how it is perceived. Colville & Pierce (2012) identified that that parents' subjective experience of their child's time in PICU, was more related to their PTSS symptoms than objective measures such as illness severity. Dow et al. (2012) suggest that a child's subsequent emotional distress is influenced by how they process and remember their experiences, which can be attributed to their stage of cognitive development. Therefore, it is important to consider the age of the child, particularly as a review of paediatric emergency hospital admissions shows that the majority were for children between 1-4 years old (Keeble & Kossarova, 2017). Similarly, general admissions to PCC are mostly for children under the age of four (NHS, 2017).

## 1.4 Developmental View of Critical Illness

Infancy and early childhood are periods of rapid development (Department for Education [DfE], 2021). Therefore, CI may disrupt a child's trajectory as they could spend significant periods of time in hospital and recovery. It is widely accepted that a child's early experiences can have an impact on later development (DfE, 2021; Tierney & Nelson, 2009).

Views differ on how young children may experience CI and time in hospital. Young children, who are likely not to have developed complex language production systems, may be less able to process and understand why they are exposed to traumatic medical activities (Locatelli, 2020; Nelson & Fivush, 2004). However, Salmon and Bryant (2002) suggest that due to their developmental stage, young children may not process traumatic events in the same way as older children and adults. The authors postulate that for young children, they may not understand the severity of their experience, and are unlikely to remember them. They also propose that young children are more reliant on prompts and cues from others to remember and recall their experiences. Therefore, the way families construct their experiences is significant, and warrants further investigation.

### *1.4.1 Children's Understanding of Illness*

Research highlights that parent-child socialisation shapes a child's understanding of illness and health (McIntosh & Stephens, 2012). In light of sociocultural theories of learning and development (Vygotsky, 1978), McIntosh & Stephens (2012) propose children's primary sociocultural context is their family. Therefore, the family's beliefs and experiences can impact on how young children construct meaning.  Carnevale (1997) suggests that children's understanding of their own health, and the impact this has on their identity, is also largely shaped by their parents. When a child experiences a CI, Carnevale argues that both the child and their family go through their own process of "unmaking and remaking" (1997, p.52).

## 1.5 Theories of Childhood Illness

As recognised in the PICs-p framework (Manning et al., 2018) children's experiences of illness and recovery are strongly interrelated with the family relationships and responses. However Rodríguez-Rey & Alonso-Tapia (2019) recognise that there is a pathologising view of CI across the literature, despite recognition that many children recover and cope well. Therefore, the researcher drew on models and frameworks which relate to the child in the context of the wider system and resilience.

### *1.5.1 Family Systems Illness Framework*

Family Systems Illness Framework (Rolland, 1994) built upon family systems theories and recognises that family members interact with and influence each other's behaviour. In the context of an illness, the framework proposes that illness should be considered in light of the biological, psychological and social systems within which humans exist. Rolland & Walsh (2006) proposes that the patient, family and community health care providers should be considered as one interacting ecosystem.

### *1.5.2 Bronfenbrenner's Ecological Systems Framework*

Bronfenbrenner's (1979) ecolo\gical systems theory of human development demonstrates how a child interacts with their wider environment. Within this view, human functioning involves a complex interaction between the individual, family, community and larger systems. According to the theory, the child is at the centre of multiple inter-related systems. The microsystem, is the most significant for the child, as it focuses on the interactions between the child and their immediate environment including their family. This is also where events such as illness may impact on the child and their microsystem. The second layer, is the mesosystem, which represents the interactions between the child's microsystems, for example their parents, school and health. Then there is the exo-system, which represents community services and professionals working with the child outside of their direct systems. The researcher recognised similarities between both Bronfenbrenner and Rolland's' frameworks that can be applicable to how a child and their family experience illness, as this is experienced not only in the family, but impacted by their experiences with wider systems including health and education.

### *1.5.3 Resilience Theories*

Resilience is a familiar term across health care, education and mental health. Windle proposed "resilience is defined as the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma." (2010, p.1) and it is considered more than just the absence of adversity (Masten, 2018).

Ungar (2021) recognises the importance of considering resilience within an ecological perspective, highlighting the importance of culture and context. Walsh (2006) also looks at resilience in light of Bronfenbrenner's (1979) framework to create the Family Resilience Framework (FRF, Walsh, 2006). This recognises that the complex interactions can impact on how a family and an individual within that family, handle stressful life experiences. Applying the FRF, Rolland & Walsh (2006) recognise that in the context of CI, it involves "struggling well, effectively working through and learning from adversity, and integrating the experience into the fabric of individual and shared lives" (p.527). This involves recognising that family members can support a child's resilience in the face of CI and that the family, as a system, can experience improvement.  Rodríguez-Rey & Alonso-Tapia (2019) suggest that following a traumatic event, such as CI, there are also accounts of people experiencing positive psychological change. This has been conceptualised as 'post-traumatic growth' (PTG) and refers to the growth people experience as a result of effectively coping with trauma (Tedeschi & Calhoun, 2004).

### *1.5.4 Narrative Theories*

Narratives are the way that we structure and understand our lived experiences (Bruner, 1991). As McAlpine (2006) suggests, the way that individuals tell stories about themselves and their past, provides insight into how they make sense of their experiences. The researcher was interested in how narrative accounts of illness can provide deep insight into the worlds of patients and their families (Skott, 2001) which is a key aspect of the current research. The researcher will further explore narrative approaches and how they underpin the current research in Chapter 3.

## 1.6 Researcher's Position

### *1.6.1 Educational Psychology Practice*

Within EP practice, it is common to ask about a child's developmental history when gathering information about a case. As a Trainee Educational Psychologist (TEP) the researcher works with an interactionist and systemic view of child development, recognising how the child and their environment interact as they develop (Bronfenbrenner, 1979). The researcher recognised that within their practice, there appeared to be a lack of discussion regarding children who had experienced and recovered from CI in their early years, despite the literature recognising that there are often residual adversity and challenges (Abela et al., 2020).

The researcher reflected that this was an area that was relatively unknown in their work as a TEP. As mentioned earlier, thousands of children are admitted to PCC annually, many of whom are of school or preschool age. The researcher also acknowledged, that there was a lack of legislation related to considerations that are made in school to support the child and their family, unless there were complex ongoing care needs or disabilities (DfE, 2015). The researcher was curious as to whether a lack of discussion around this population may result from a lack of overlap between health and educational fields or that children and families do not require support in the school context.

### *1.6.2 Personal Position*

The researcher held an interest in this area before becoming a TEP as a result of personal experiences, therefore this section will be written in first person. I have a younger sibling who at 18 months old was diagnosed with a benign brain tumour. Although surgery successfully removed it and she made a full recovery, this experience had a long lasting impact on my sister and family. I have always been interested in her experiences as, at the time, she did not understand what happened to her. I recognise that the narrative within the family, although positive, has shaped her understanding of that time and her identity. I am interested in what stories she would have told about her experiences had she been asked as a child. These events inspired me to consider what stories are told about CI from differing points of view.

## 1.7 Rationale and Aim of Current Research

This research aims to explore how early childhood CI is experienced and understood by children and their families through a narrative approach. The current research recognised it was important to include and combine the differing perspectives of the parents, children and teachers, to provide a rich understanding of early childhood illness. The research is concerned with what the child understands and considers to be part of their own story, but also how that knowledge was acquired. The current research has the potential to have an impact on the way that health and education services work together to support young children and their families after CI and admission to PCC. The research findings may also influence the narrative that surrounds children who have survived a CI as we gain a deeper understanding of how these experiences are constructed by the child and their families and shed light on what is meaningful for families in this situation.

# Chapter Two: Literature Review

## 2.1 Chapter Overview

This chapter outlines a review of the literature in relation to the lived experiences of children and their families following a period of CI or injury, particularly focused on their experiences following discharge from hospital. The chapter begins by outlining the systematic search process, followed by an overview and critical analysis of the literature. A summary of the research in the field will then be discussed and any gaps in the research base will be identified to provide rationale for the current research.

## 2.2 Systematic Literature Review

A systematic search of the literature was conducted in July 2021. The literature review aimed to evaluate the current research base in relation to the following review question:

*What do we know of the experiences of children and their families following a period of critical illness or injury in childhood?*

### *2.2.1 Defining Search terms*

An initial scoping review of the literature took place in November 2020 which helped the researcher identify the search terms to be used in the final search. Research in this area is largely conducted by medical professionals and therefore the search terms were adjusted to try to focus on the psychological lived experiences of participants. The researcher included the general terms of ‘illness or injury or critical care’. This ensured the research included children who had a variety of experiences as some research referred to the hospital admission as critical and some referred to the injury or illness as critical. The final systematic search terms can be seen in Appendix A.

### *2.2.2 Literature Search Process*

A systematic literature review following guidelines from the PRISMA statement (Page et al., 2021) was conducted across a range of databases that were considered most relevant to the area of research. The researcher used EBSCO Host to search:

- APA PsychINFO
- Academic Search Complete
- Child Development and Adolescent Studies
- CINAHL Plus

The researcher then sought additional papers through the following databases: Science Direct, Scopus and PubMed. A summary of the literature search strategy can be seen in Figure 1. The search terms were entered into each database and limiters and search criteria were applied, full details of which can be found in Appendix A. The research focused on the most recent and up to date literature, which would represent the current medical practices. The researcher did not limit the age of participants as she wanted to capture the views of parents and family members of children, however using the search terms (paediatric or child*) minimised the amount of papers which were focused on adults who had been in hospital. Additionally, using search or thesaurus terms was difficult due to the variation in the subjects in the literature and the researcher did not want to exclude any papers that might have been relevant.

Following the application of the first set of limiters (English; 2010-2021, peer reviewed journals), the researcher screened the title and abstracts of the remaining papers to decide whether to read them fully. In total 32 papers were considered for full text review in light of the inclusion and exclusion criteria (see Table 1). However two of these were inaccessible, despite requests via the Inter Library Loan.

The researcher then conducted a hand-search of all of the papers to identify any additional relevant papers to include in the review. Following a hand-search of the Atkins et al. (2012) paper, the researcher identified and included the Atkins et al. (2020) companion paper. In the wider hand search, no additional articles were identified that met the criteria for inclusion in the final review. The researcher then conducted a search using Google Scholar to explore the literature on children and their families' experiences.  No additional relevant papers were identified based on the inclusion criteria.

The researcher conducted a follow up search on 28.02.2022 to check whether any additional research papers had been published since the last review. The researcher identified Jones et al. (2022) which is one of three papers produced by the authors using the same data set, all of which are included in this review.

**Table 1**

*Literature Search Inclusion and Exclusion Criteria*

| **Inclusion Criteria** | **Exclusion Criteria** |
|---|---|
| Articles written in English. | Articles not written in English. |
| Articles published from 2010 onwards to focus on the most recent research in the field. | Articles published before 2010. |
| Articles published in peer reviewed journals in order to ensure articles are of high quality. | Articles not published in a peer reviewed journals. |
| Research had taken place. | Prospective overview or pilot studies. |
| Articles that focus on the child and/or their family post-discharge from hospital. | Articles that focused on the child and/or their family whilst still in hospital. |
| Articles focused on children who had been unwell or injured due to accidental or natural causes. | Articles focused on neglect or abuse, palliative care, death or a mental health related hospital admission. |

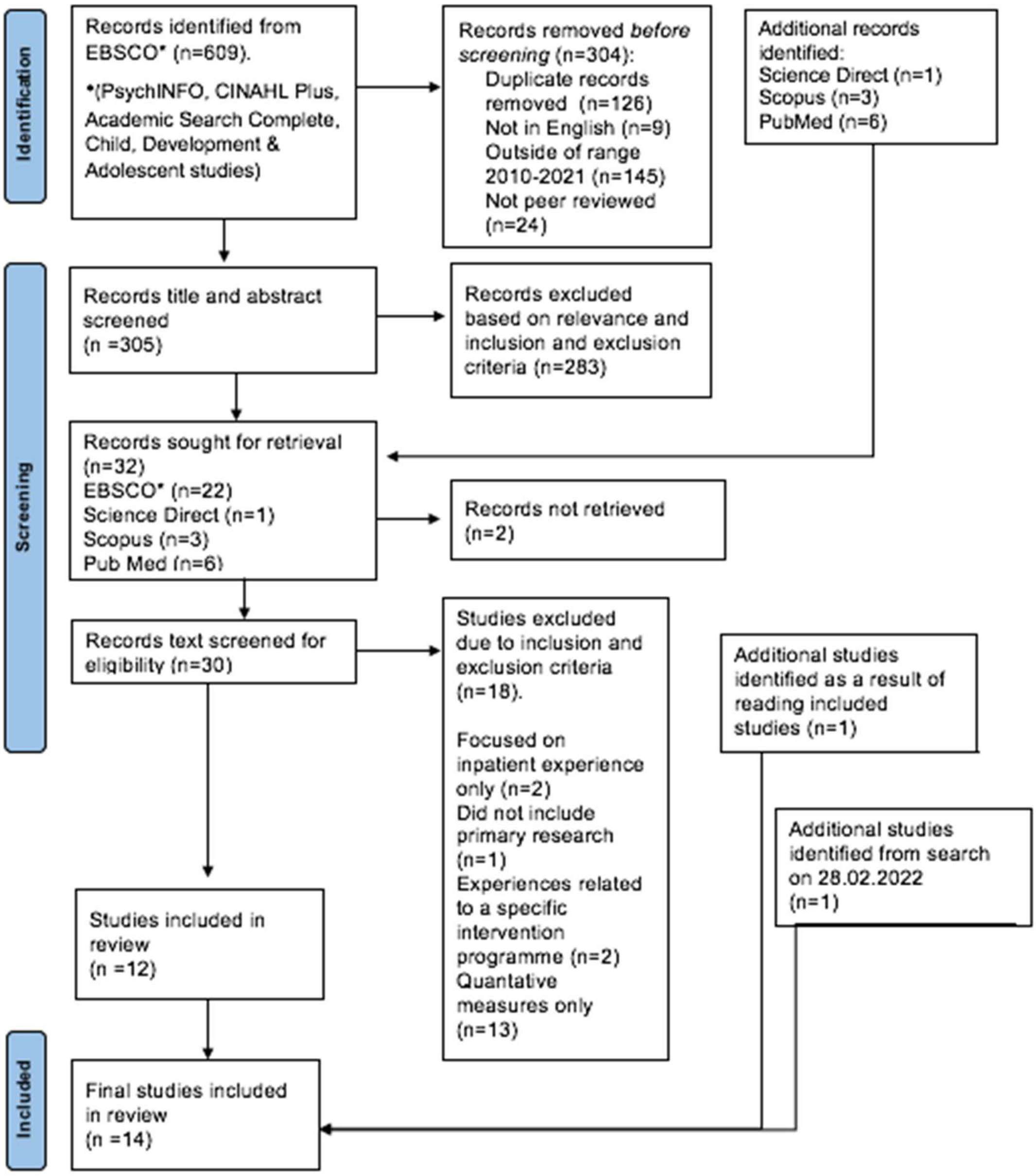
| | |
|---|---|
| Articles where the patient admitted was a child. | Articles where the patient was only admitted as a pre-term baby or an adult. |
| Studies that were qualitative or mixed method. | Quantative data only. |
| Primary research which included the child and/or their family. | Systematic or scoping literature reviews, Studies based on third person or medical record data or secondary data. |
| Studies focused on the lived experiences of the child and/or their family. | Studies focused on testing or measuring an intervention, evaluating services, experiences of professionals, or patient medical outcomes. |
| Full text access available. | Unable to access article despite inter library loan request. |
| Focused on the psychological, social, and emotional experiences of children and/or families. | Focused on medical or health outcomes only. |

In line with the researcher’s ontological and epistemological position, which is further explored in the following chapter (3.2), the current research is underpinned by narrative and social constructionist theory. From this perspective, the current review only focused on qualitative pieces of research which take a holistic view of participants’ lived experiences and how they interpret these experiences.

Following the literature search process detailed in Figure 1, 14 papers were identified to include in the critical review based on the inclusion and criteria and their relevance to the review question. A summary of the key points for each paper can be seen in Appendix B.

***Figure 1***

*Literature Search Strategy*



## 2.3 Critical Review of the literature

Once the final studies had been identified, the articles were critically appraised to determine the validity, trustworthiness and value of the research. Booth, Sutton,

& Papaioannou (2016) note the importance of using a quality assessment checklist to guide this process. The Critical Appraisal Skills Programme (CASP, 2018) checklist was chosen as a framework to guide the researcher in this process. The CASP contains 10 questions in relation to three areas: validity of the study, the results and the research value. Each question has prompts to guide the researcher in the appraisal process. Critique of the papers can be seen in Appendix B.

### *2.3.1 Thematic Approach to Review*

The researcher adopted a thematic approach to reviewing the literature by reading the articles in order to identify common themes and topics. Due to the similarities in the findings across the literature, this proved to be an effective way of organising the articles. The findings are organised into the following themes:

1. The impact on the child and their family
2. Ways of coping
3. Experiences of support and services

## 2.4 The impact on the Child and Their Family

The literature acknowledges that children and their families experienced a range of physical, functional, emotional and cognitive implications as a result of their illness and/or injury. Many of these psychosocial implications continued once the child was discharged from hospital and had made a full physical recovery.

### *2.4.1 Biopsychosocial Model*

Atkins et al. (2012; 2020) conducted a piece of research looking at the recovery trajectories of children who had been admitted to PICU and produced two papers. The authors conducted interviews with parents (n=13) and young people aged between 5-17 years old (n=5), between 8-18 months after their PICU admission. The 2012 paper adopted a constructivist grounded theory approach to build on Engel's (1977) biopsychosocial model, which addresses the interconnection between biology, psychology and social and environmental factors on one’s experience of illness.

The authors suggest that following discharge from hospital, families experience recovery along a biological, psychological, and social trajectory by which children and their families experience and prioritise different aspects of their recovery over time. This is demonstrated through a visual model (seen in Figure 2). Initially, the child’s physical recovery is the priority. Once their physical health improves, the family begin to process the psychological and social impact of what has happened. These authors suggest that all three components of the recovery are important for families and challenge the medical focus on physical recovery.

Atkins et al. (2012) acknowledge that the model is based on the experiences of seven white British families and one Asian British family and therefore may not be applicable to families from other cultures in which illness may be conceptualised differently. Additionally, the authors refer to the interactions between the child and their family across the three strands, but do not explore this in depth. A strength of the paper is that the researchers involved participants from the target sample pool to develop the methodology and interview schedule. For children under 12 (n=2), the researcher used activities such as a hospital play set and drawing materials to make the interview interactive and relatable to the child. Additionally, a rigorous data analysis was conducted in which data saturation was reached and participants were invited to review the findings and offer feedback.  This research was the only reviewed study which was underpinned by a theoretical framework. Thus, this study provided a more psychological understanding of the participants’ experiences than the others reported.

**Figure 2**

*Biopsychosocial Model for Recovery*

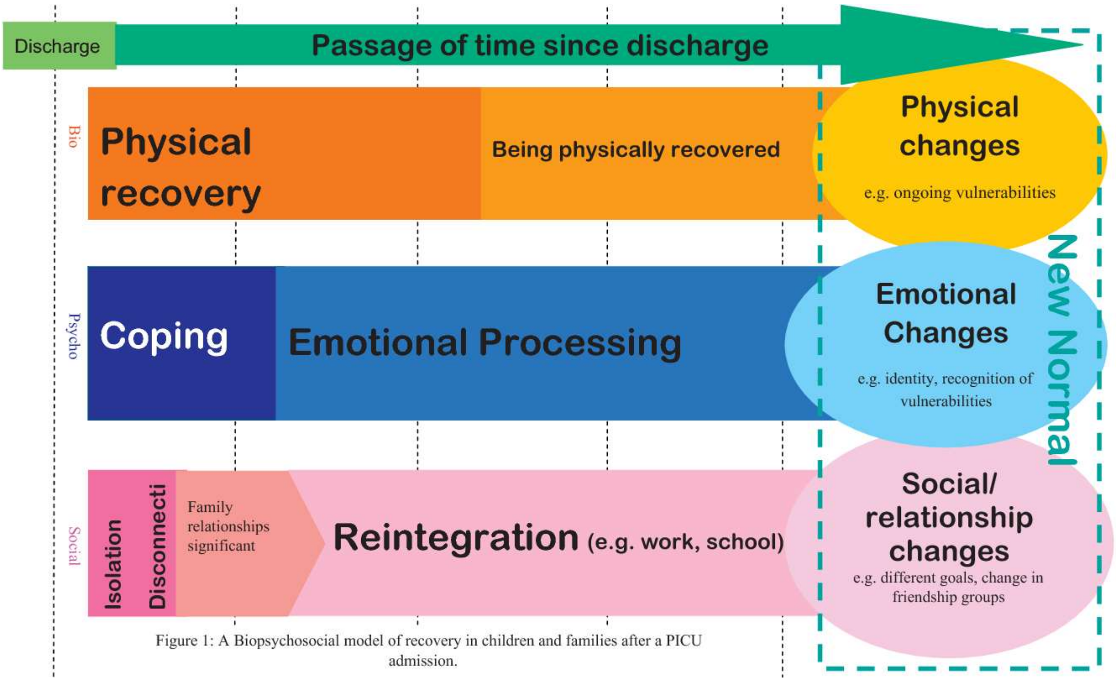


Figure 1: A Biopsychosocial model of recovery in children and families after a PICU admission.

Note. From “A ‘biopsychosocial’ model for recovery: A grounded theory study of families’ journeys after a Paediatric Intensive Care Admission” by Atkins, E., , G., & John, M. (2012). *Intensive & Critical Care Nursing*, *28*(3),133–140. https://doi.org/10.1016/j.iccn.2011.12.002

Although the model is based on children who had CI and were admitted to UK PICUs, similar findings exist in other populations of children. Parents of injured children (Foster et al., 2019; 2020; Jones et al., 2021) described that psychological and emotional needs were only prioritised after some time at home, once the child had started to stabilise and recover physically. The authors consider a biopsychosocial model as a means of explaining their experiences.

Foster et al. (2019; 2020) conducted two studies using semi-structured interviews with parents of injured children in Australia at six months (n=30) and two years (n=22) post-discharge. A strength of these studies is that the participants included a higher proportion of fathers than other studies in this review and include demographic information. Although the researchers conducted two pieces of research at two time points, they did not use the same sample so direct comparisons cannot be made between participants’ experiences over time. However, the findings indicate that at both 6 months and 2 years post-discharge, parents’ experiences and priorities follow the biopsychosocial trajectory, as once the child was making good progress physically, the psychological and emotional impact of the injury on their child was more of a priority.

Similarly, findings were found by Fayed et al. (2020) who conducted interviews between 3.5 to 12 months post-discharge to determine whether, following a period of CI, young people and their families shared similar priorities to those determined by medical researchers. Fayed et al. (2020) interviewed 20 parents, including 19 mothers, and only 1 young person, although they mention that other young people were present during the interviews. Therefore, the findings can only claim to represent the views of mothers of critically ill children. The authors identified that participants prioritised the survival and functional recovery of their children before focusing on the cognitive and emotional recovery. The authors recognised that although parents’ priorities initially are similar to the ICF-CY domains of functionality and health, their priorities change over time, aligned with the biopsychosocial model.

### *2.4.2 Impact on the Child Following Discharge from Hospital*

Jones et al. (2020; 2021; 2022) focused on the experiences of both children and their parents who had experienced a traumatic injury in childhood across trauma centres in the UK. The authors used purposive sampling to ensure that the participants varied in age, and had experienced a range of different injuries, in the hope of representing the population in trauma centres. All three of the papers focused on the same relatively large sample (n=32). However, they note the limitations as many of the parents were mothers (n=18) and they were not able to identify demographic or ethnicity data. The authors acknowledge that this means the research does not necessarily represent population diversity, which is an issue, as it is thought that cultural factors have an impact on the way that individuals conceptualise recovery (Atkins et al., 2012). However, the research involved both the parents and children themselves which is a strength. The sample included 13 children aged between 8-16 years old and their parents or guardian (n=14). As one of the few studies to include both parent and child participants, Jones et al. (2020; 2021; 2022), made some ethical considerations when involving children. They allowed them to take part in a way that felt comfortable, i.e. with or without their parents. In total, 8 children were interviewed by themselves, with another 5 having interviews with their parent or guardian. The authors acknowledge that they adapted the interview questions to suit younger participants. However, they do not clarify what adjustments were made, what age was considered young, or how old were the child participants who took part directly. Another 5 parents took part without their children, either because the children were deemed to be too young, or it was thought it might be too distressing for them to take part in an interview. The authors thematically analysed the interviews across three different areas and separated the research into three papers: the needs of children following injury (2020), the impact of injury (2021) and educational support needs (2022).

Their findings indicate that following hospital discharge, children experienced a range of additional physical symptoms including: nausea, sleep disturbances, mobility issues, fatigue and hallucinations. The authors postulate that these symptoms impacted on the child’s psychological wellbeing and behaviour. Many of the young people reportedly experienced a range of behavioural, emotional and social difficulties, including depression, loss of confidence and frustration (Jones et al., 2021). Negative emotions were particularly related to restriction and difficulty resuming activities.

A similar link between functioning and emotional sequalae was found by other research included in this review. Fayed et al. (2020) noted that children’s quality of life in the months after hospital discharge was heavily influenced by their functionality and capacity to take part in activities. Foster et al.’s (2019; 2020) sample reported that children’s emotional and physical recovery were closely related, as once they recovered functionality, they were more emotionally stable. However, two years post-discharge, a third of parents reported that their children still experienced anger, depression and anxiety, illustrating the potential long-term impact of a CI or injury in childhood.

The relationship between physical and emotional recovery was demonstrated in Williams et al.'s (2018) study of parents of children who had experienced a range of neuro-critical illness in childhood. Some of the parents in this study believed their children's high levels of fear and anxiety, following neuro-critical illness, impacted on their engagement with life and overall wellbeing. The authors facilitated focus groups with 16 parents of children who had a child admitted to paediatric neurocritical care within the last 1-8 years. Most of the parents were white mothers, although they included participants from a range of socio-economic status.

Williams et al. (2018) also reported that many of the parents described their children as having experienced PTSS and that their fear and anxiety manifested in anger and internalising and behavioural problems.  Although it is a strength that the study included parents up to 8 years after  discharge (to evidence the long term implications of neuro-critical illness on the family), it is hard to determine to what extent these symptoms are pertinent over time. This is because the sample does not allow for direct conclusions to be drawn about individual parents at specific points in time.

Similarly, McKevitt et al. (2019) interviewed 12 parents of childhood stroke survivors between a year to 5 years later. However, the authors do not provide any demographic information, therefore it is not clear whether they included both mothers and fathers. Additionally, the researchers acknowledged that they did recruit two young people, but do not provide explanation as to why their data was not included in the paper. A strength is that the researchers reviewed the interview schedule with parents and a young person before conducting the research. Similar to Williams et al. (2018), the authors report that child stroke survivors experienced a range of psychological and emotional problems including aggression, low mood, anxiety and self-harm. However, they do not draw conclusions as to what parents specifically believed caused their children such emotional distress. The authors highlight that the children in this study did continue to experience varying neurological deficits as a result of their strokes, which did impact on their ability to engage with activities. There was some suggestion  that children experienced post-traumatic stress symptoms in relation to specific memories and flashbacks to their time in hospital (Egberts et al., 2020; Jones et al., 2021), which they found particularly traumatic.

### *2.4.3 Child's Perspectives on Their Experiences*

Children's views are far less prominent in the literature. Most of the literature is based on parent reports of the period of illness and injury and the impact on their child. The papers that included both parent and child views did not provide enough detail for the researcher to identify to what extent the themes identified are based on the child or parents' views of the experience. Therefore, it is hard to determine what the child's views are, irrespective of those of their parents (Atkins et al., 2012; 2020; Jones et al., 2020; 2021; 2022). This has implications for drawing conclusions about how the children in these papers experience recovery.

Within the review, two papers focused on the experiences of children only (Egberts et al., 2020; Manning et al., 2017). Manning et al. (2017) explored the long-term psychosocial wellbeing of children survivors of CI through a narrative approach. Nine children (aged between 6-15 years old) took part in the research between 6-14 months following their discharge from PICUs in England. The authors adopted a child centred approach, using tools including photo and graphic elicitation techniques as a means of allowing participants to express and explore their experiences. This is a strength of the research, in which efforts were made to include young people in the design and data collection.

The authors reported that children's desire to return to their normal 'able' selves caused them distress when they experienced residual physical, social and emotional adversities. Through their stories, children expressed anxiety and fear related to their time in the PICU and feelings of confusion and doubt following discharge. For some children, the realisation that they could have died resulted in psychological distress.

The researchers address issues of credibility and trustworthiness, particularly prevalent with narrative analysis, in which the researcher plays a role in creating a story with the participants. The research took place over a period of 6 months, allowing the researcher to collect vast amounts of data and to spend time developing a rapport with the participants (Manning et al., 2017).  This is an insightful piece of research, which provides a rich and detailed understanding of the experiences of young people who have spent time in a PICU.

Egberts et al. (2020) also focused on the voice of children who had been hospitalised due to burn injury in the Netherlands and offers insight into their experiences. Participants aged between 12-18 years old were interviewed between 4-17 months following discharge from hospital. Similarly to Manning et al. (2017), the authors acknowledge the need to build a rapport with young people and address ethical issues around distress and consent. It may be that due to the older age of participants, the author felt that semi-structured interviews were appropriate as no adaptions were made to data collection related to age. The participants experienced vivid memories of their time in hospital and the accident that occurred, which they described as intrusive. The authors claim that, over time, some of the young people felt they had returned to their ‘pre-burn self’, whilst those experiencing long term psychosocial difficulties, reported feeling cautious and hypervigilant in situations they perceived as dangerous.

### *2.4.4 Impact on the Parent Following Discharge from Hospital*

As aforementioned, the majority of the research was focused on parents’ perspectives of how childhood illness and injury impact on the child and their wider family. Across the literature, emotional adversity was a common theme experienced by parents. Parents experienced high levels of anxiety and worry about their child’s recovery and wellbeing (Fayed et al., 2020; Jones et al., 2021; McKevitt et al., 2018, Williams et al., 2018; Wray et al., 2018) and described the recovery journey as an emotional rollercoaster (Foster et al. 2019; Jones et al. 2021). Across the literature, parents’ wellbeing was evidently inter-related with their child’s, as one parent described that *“if she’s alright, then we’re alright”* (Jones et al. 2021, p.620).

Psychological disorders were commonly attributed to the traumatic experience of seeing their child in hospital (Jones et al., 2020) and realising they might not survive (Fayed et al 2020). Across the literature parents acknowledged that they did not process the severity of the situation until they returned home as they were in survival mode during the acute stage of illness or injury. These findings can be compared to the coping stage of the biopsychosocial model (Atkins et al., 2012).Once home parents also experienced stress, as they had to adapt to the emotional, behavioural and psychological difficulties that their children presented with following discharge from hospital (Foster et al., 2019; Jones et al., 2021; Wray et al., 2018).

Parents also reported experiencing guilt and a sense of hopelessness at times, when they were unsure what they could do to help their child (Atkins et al., 2012; 2020; McKevitt et al., 2018; Williams et al., 2018). Some parents experienced grief as they mourned the loss of who their child was before, which was particularly present if their recovery was slow (Foster et al., 2020). Williams et al. (2018) also highlighted the potential long term impact of CI on parents, as more than half of their sample described experiencing ongoing high levels of stress and anxiety akin to PTSD. Similarly, Jones et al. (2021) and Wray et al. (2018), report parents experienced PTSD and physical exhaustion from having to support their child both emotionally and physically. Parents across the literature reported neglecting their own mental health and physical care needs (Foster et al., 2019).

### *2.4.5 Experiences of Social Exclusion and Isolation*

Social isolation and exclusion were encountered by both children and their parents following a period of CI or injury. Wray et al. (2018) gathered data from 73 mothers through an online forum for parents whose child had cardiac surgery as a result of heart disease. The majority of the parents reported that their children were infants at the time of their surgery. The study intended to explore parents' experiences of discharge, and post-discharge. The authors acknowledged that an emerging theme was a sense of physical and social isolation. The authors attributed this partly to the long periods of time they spent at home due to anxiety about keeping their children safe. Additionally, parents felt misunderstood by others and found it difficult to interact with parents with healthy children due to perceived stigma.

Wray et al. (2018) acknowledge that due to the use of an online forum, the authors could not identify specific details about the participants or ask clarifying questions. However, they reflected that using an online method may have encouraged participants to share honestly about their experiences and the findings did offer insight into the experiences of families following a CI. The intention was to gather data from a wider and harder to reach audience, who may not have wanted to take part in formalised research. However, participants were mostly white British mothers, in line with much of the research in this area. Difficulties talking to others about their experiences and the resulting sense of social isolation was found in some of the other papers. Both children and parents in the literature described difficulties with talking about their experiences, which resulted in feelings of 'difference' (Atkins et al., 2012; Manning et al., 2017). Manning et al. (2017) found that older children who feared stigmatisation from their peers were reluctant to talk or share their experiences with their friends who had not been directly involved.

For children, their experiences of social isolation were in part attributed to missed schooling. Also the psychological impact of their injury meant they were reluctant to socialise (Jones et al., 2021). For some children reintegrating was challenging due to a sense of disconnect from their peers (Manning et al. 2017; Atkins et al., 2012). Children who had changes to their appearance felt self-conscious, which impacted on their social engagement (Egberts et al., 2020; Jones et al., 2021).

Parents in McKevitt et al.’s (2018) study reported that the way other people perceived their children impacted on their ability to socially participate in activities.

### *2.4.6 Changes to Children’s Identity*

Young people experienced changes to their identity and found their period of illness or injury impacted on their self-perception and confidence (Atkins et al., 2020; Manning et al., 2017). Both papers recognised that a CI disrupted a child’s development and caused a physical, emotional and social transformation, which children tried to understand in the context of their illness. This shift resulted in a change in how they viewed themselves and a recognition that their interests and views on the world had changed.

### *2.4.7 The Child and Parent Relationship*

The power of the parent-child relationship is evident throughout the literature as both the child and parent’s wellbeing are highly interlinked. Foster et al. (2020) reflect that parental wellbeing and availability to support their children can have a significant impact on the child’s recovery. Children in Egberts et al.’s (2020) paper described how their parents were a huge source of support throughout their recovery, and that they experienced improved family relationships as a result of the time spent together.

Foster et al. (2019; 2020) recognised that the age of the child had an impact on the way parents perceived the relationship. They found that parents of infants found it difficult to assess whether the injury had impacted on their relationship because of the child’s developmental stage, whilst parents of older children reported feeling closer after the injury. Older children found relying on their parents more than usual to be challenging in Jones et al.’s (2021) research. They noted that tension arose between children and their parents regarding reintegrating into their past lives and taking part in activities as children were less risk averse than their parents.

### *2.4.8 The Impact on the Family Following Discharge from Hospital*

The literature highlights the complexity of recovery for the wider family. As Mckevitt et al. (2018) acknowledge, the impact on the family was not always obvious as their priority was on their child and their health and recovery. This is a similarity across the papers as parents noted they had little time for anything else in their lives as a result of their child's recovery, highlighting how consuming the experience can be for the entire family (Fayed et al., 2020; Jones et al., 2021).

#### *2.4.8.1 Wider Family Relationships*

Some families experienced strengthened relationships, but also a sense of disconnect due to time in hospital and changing priorities and dynamics. Williams et al. (2018) and McKevitt et al. (2019) noted that the emotional stress of the experience put a strain on the family, which resulted in a breakdown of relationships and tension. It was also noted that siblings were affected emotionally (Fayed et al. 2020) and experienced jealously and resentment due to the focus on the recovering child (Jones et al. 2021; McKevitt et al., 2018).

#### *2.4.8.2 Changing Roles*

Across the literature, parents reported experiencing ongoing changes once discharged from hospital and returning home. Parents described the impact of the illness or injury in terms of practical, financial and psychological implications for the wider family.  Lerret et al. (2017) interviewed 41 mothers and 1 father of children who had an organ transplant. Interviews were conducted at 3 weeks, 3 months and 6 months post-discharge, which is a strength as comparisons could be made across the recovery journey. The authors acknowledged that at 3 weeks, parents' main priority was trying to re-establish routines which was complicated by having to manage medication, treatment and appointments in addition to their usual parental responsibilities. At 6 months, although parents had adapted to their new roles, they still found it challenging. Other studies present similar findings in which the parents wanted to return home as soon as possible.

Parents had to give up work or change their working patterns to accommodate their child’s care needs and appointments as well as adapting their routine as a family (Foster et al., 2019;2020; Jones et al., 2021; Lerret et al, 2017; Williams et al., 2018; Wray et al., 2018). Some parents described that their role had shifted from parent to ‘nurse’ as they had to provide high levels of medical care (Wray et al., 2018).

## 2.5 Ways of Coping

Throughout the literature, parents described how they coped and overcame adversity following CI or injury.

### *2.5.1 Creating Narratives*

Atkins et al.’s (2020) paper focused on the strategies that parents and children use to cope and overcome adversity following CI. The authors suggest that for many families, recovery involved creating a narrative about their experiences of illness or injury. This enabled participants to process what had happened to them as a means of moving forward. Within their study, children reported having a sense of a ‘missing picture’, which impacted on their psychosocial wellbeing and ability to tell their story as they relied on those around them to fill in the gaps. This was a way of processing their experiences and Manning et al. (2017) found that children experienced confusion and adversity if others’ accounts challenged their own understanding. Manning et al. (2017) adopted a social constructionist epistemology, focusing on the role of narratives as a way of understanding experiences. Children talked of not only their past and present but also their future in their stories of their illness and time in the PICU. However, some children did not choose to talk about it at all. The authors attributed this to being a protective technique.

Egberts et al. (2020) found that some children avoided talking about their injury and actively avoided triggers that reminded them of what happened. However, most of the sample reported that “processing the trauma” (Egberts et al., 2020, p.6) was important as they looked at pictures of their injuries and talked about the experiences with family and friends. Egberts et al. (2020) reflect that their participants were aged 12 and older and therefore these findings may be less relevant to younger children. As the authors note, younger children are highly dependent on their parents for psychosocial support and care and arguably may experience illness or injury events differently due to their differing cognitive capacities.

Jones et al. (2021) acknowledge that having parent-child interview dyads meant that parents were able to offer insight into the child’s experience that may have not been sought otherwise and this may have influenced the scope of the interviews. This is particularly of interest in light of the idea that parents fill the gaps for young children and therefore it may be that their reported experiences are more akin to those of their parents.

### *2.5.2 Seeking Normality*

Striving for normality was identified as a priority and coping mechanism throughout the literature. Through returning home and establishing a routine, parents felt a sense of control (Foster et al., 2019) which helped them to come to terms with what had happened as they looked to the future (Foster et al., 2019; Lerret et al. 2017; McKevitt et al., 2018). This theme is explored by Atkins et al. (2012) in the biopsychosocial model (see Figure 2). Once the child is deemed to be physically recovered, the family begin reintegration into their past lives through work, school and friendships.

Children survivors of PICU, found returning to a school routine helped to alleviate anxiety as they were distracted and felt they were moving towards being a normal child (Manning et al., 2017). Atkins et al. (2020) suggest that a ‘new normal’ involves a different sense of identity and a shift in priorities. For older children and their families, they reported a need to re-establish their social roles and identity in light of their experiences (Atkins et al., 2020; Manning et al., 2017). This insight poses the question of what it is like for younger children who have a less established sense of self.

### *2.5.3 Finding Hope and Resilience*

Reviewing the literature in this field, it is evident there is a focus on problematising and pathologising the experiences of children and their families by researchers. This is arguably because the research is conducted by medical professionals with the intention of identifying unmet needs so that improvements can be made to the care provided. However, throughout the literature, both children and parents' experiences highlight that as a result of adversity, there can be positives. Jones et al. (2021) identified an additional theme of 'positive impact' from their interviews as children and parents identified that they felt a new appreciation of life. Parents described their children as brave, resilient and determined to move forward (Foster et al., 2020; Jones et al., 2021).

Atkins et al. (2020) identified that along the recovery journey, parents and children experience a shift from coping to recovering, at which point they could reflect on what had happened with a new perspective. Foster et al. (2020) recognised the importance of being resilient and that although parents did not always find it easy, they tried to focus on being strong in the face of adversity. Parents in this study also found hope by reflecting on their children's ability to adapt and overcome challenges.

Stories of hope and resilience were also evident in children's experiences. Children described a sense of gratitude and fresh perspective that helped them to move forward and feel better about what happened to them (Egberts et al., 2020; Manning et al., 2017). Children described "living for the today" (Jones et al., 2021, p.620) in which their approach to life had given them insight and increased empathy.

## 2.6 Experiences of Support and Services

Much of the literature explores the participants' experiences of support and ongoing care they received from both professionals and the wider community. Jones et al. (2020) focused specifically on the needs of children and their families after a traumatic injury and found that despite participants' unique circumstances, they expressed similar needs post-discharge. Families' needs included: "education and training to help understand the injury and how to manage it, effective communication, access to sufficient services, support to coordinate care and positive partnerships with professionals" (Jones et al., 2020, p.7). The authors identified that parents who had good access to health care professionals and felt supported with their child's medical care found it easier to adapt at home. Similar findings were reported in other papers in this review (Atkins et al., 2020; Lerret et al., 2017; McKevitt et al., 2018; Wray et al., 2018).

### *2.6.1 Access to Services and Support*

Parents across the literature had inconsistent experiences of support post-discharge from hospital. Many parents report being offered psychological support whilst still in the acute phase of their child's illness or injury, at which point they were not focused on psychological wellbeing (Jones et al., 2021; Wray et al., 2018). In line with the biopsychosocial model (Atkins et al., 2012), psychological difficulties are more evident following discharge from hospital, although parents often reported that this was when support was no longer available (Foster et al. 2020, McKevitt et al., 2018). The studies which took place in the UK are of particular interest to the researcher as they offer contextual insight relevant to the current research.

Wray et al. (2018) concluded that parents of children who had heart surgery were positive about the care they received whilst in hospital. However, most parents retrospectively shared that they were given insufficient information about what to expect post-discharge and were unaware of services available to them, which exacerbated feelings of isolation. Parents valued receiving training, accessing support groups, and having ongoing support from their local hospital to support them in caring for the child.

Parents' varying experiences of post-discharge support suggest a discrepancy between the quality of the services and support offered to families depending on where they live, the nature of their illness or injury and the level of their ongoing challenges. Although not explicitly mentioned in the literature, the findings can be considered within Bronfenbrenner's (1979) systems framework in which the relationships between the child, their family and wider systems impact on their ability to cope and manage.

A criticism of the literature is that there is very little reference made to the demographic information of parents in terms of their experiences. Some studies make note of the socioeconomic standing and ethnicity of participants, yet this is relatively unexplored in relation to their experiences of care and emotional wellbeing. Jones et al. (2020; 2021) note that the experiences of families are shaped by their wider system in which access to resources vary. Considering that across the literature some parents considered accessing private services to fill the gap in the support, there is little comment on this only being an option for families who could afford it. They highlight the need for a multidisciplinary provision offering targeted support for post-discharge care, where key professionals can mediate and support families to access appropriate education and medical care.

### *2.6.2 Medical Professionals*

Reports from both children and their parents indicate that the quality of the relationships they have with medical professionals was important, particularly when the family felt unsure of what to expect (Foster et al., 2019, 2020; Jones et al., 2020; 2021; McKevitt et al., 2018; Williams et al., 2019; Wray et al., 2018). Parents reported seeking and valuing medical advice and acknowledged that professional information influenced the way they constructed their view of their child and the experiences (Jones et al., 2020; Mckevitt et al., 2018; Wray et al., 2018). These participants valued medical involvement and advice due to fear and uncertainty about their child's recovery. However, families' experiences of medical information were mostly focused on the physical aspects of recovery and some of the information felt inaccessible due to its medical language. This was often incongruent with the parents lived reality of caring for their child psychological and emotionally (Jones et al., 2020; Wray et al., 2018).

### *2.6.3 Returning to Education*

While papers refer to returning to school as a milestone on the recovery journey, there is a lack of focus on school adjustment, despite the majority of the sampled children being of school age. Two pieces of research focused explicitly on the experience of returning to education (Jones et al., 2022; McKevitt et al., 2018). These papers are of particular interest to the current study as they were conducted in England. Jones et al. (2022) identified that as a result of their impaired cognitive ability, poor concentration and memory loss, many children found returning to school difficult. The authors also identified that children often miss prolonged periods of school due to their injuries. Childhood stroke survivors were described as experiencing difficulties with fine motor skills, clumsiness and fatigue which all impacted on their ability to engage with their learning and social participation (McKevitt et al., 2018).

Parents identified that returning to school was a challenge for the family. They expressed anxiety around the risks and concerns about appropriate support being in place as their child's needs were not always apparent (McKevitt et al., 2018). As the authors argue, schools may not always have a clear understanding or expectation of how to support a child following a critical injury or illness in the way they are prepared for the associated challenges of neurological disorders such as autism or ADHD (McKevitt et al., 2018). In both studies, parents had to educate staff on the nature and implications of their child's experiences, particularly when it was no longer visible but there were still residual emotional and cognitive implications. Parents reported that when their child's needs were more profound, the support at school was more robust than if their needs were mild. This has implications for bridging the gap between medical and education support services (Jones et al., 2022).

## 2.7 Conclusion

This literature review sought to identify what is known about the experiences of children and their families following a period of CI or injury in childhood. The research highlights that childhood CI has implications for not only the child, but also their wider family. The researcher identified three overarching themes; impact of illness or injury, ways of coping and experiences of support.

Parents and children across the literature reported that the illness impacted on them physically, psychologically and socially. The literature recognises that these implications are evident from acute onset, to years later, highlighting how much of a significant and life changing event childhood illness can be. A key finding was that parents' wellbeing was highly dependent on how well their child was functionally physically and emotionally. Additionally, the literature recognises that despite these adverse experiences, children and their families do cope, drawing on their own resilience and resources. Participants acknowledged the importance of being able to talk about their experiences as a means of understanding and processing what had happened over time. The research in this review highlights the complex trajectory of recovery in line with a biopsychosocial model (Atkins et al., 2012). Throughout the literature, parents' experience of support post-discharge was a prominent theme, as they had to navigate their child's recovery and it was important to their recovery to be able to access appropriate services and information.

### *2.7.1 Summary of Literature*

A strength of the research is that many papers used purposeful sampling, which meant that a range of childhood illnesses and injuries were represented, similar to PCC hospital admissions. The findings across the literature were comparable, despite including a range of heterogeneous injuries and illnesses. Across the literature, studies have used differing qualitative methods to develop an understanding of the experiences of families following a variety of critical illness and injury. A strength of the approaches used meant that all of the papers included used participants quotes, which added richness to their findings. This allowed for insight into how overwhelming and complex the recovery journey is for both the child and their family. Additionally, it provided transparency as to how the researchers came to their conclusions.

A limitation across the literature is that despite including parents of children of a range of ages, minimal comparisons are made regarding the age of the child. Therefore, it can be hard to determine whether the families' experiences are the same or different depending on the age of the child. This is a critique of the seven papers which involved child participants, as the majority of children were aged over 10 years old at the time, despite high levels of paediatric hospital admissions happening for younger children (Atkins et al, 2012;2020; Egberts et al., 2020;Jones et al., 2020;2021;2022; Manning et al., 2017). Although some studies did include a couple of participants who were 6 years old, they do not make clear comparisons between the ages.

## 2.8 Gaps and Rationale

Children and their families' stories have been explored in some of the research using exploratory and participant-led approaches (Atkins et al., 2012;2020; Manning et al., 2017). Yet there is paucity of research looking at the experiences of children and their families and further exploration is warranted to develop an understanding of their individual experiences. Therefore, the current research intends to listen to the stories of those who have experienced a period of CI, as they wish to tell it.

A clear gap in the research is the inclusion of the child's voice, as only two out of 14 papers included provided clear detail on how children experienced illness or injury. Five out of 12 papers included both parents and child participants, but did not allow for clear comparisons of the experience from these different perspectives, as all participants findings appear to have been analysed and presented together. Therefore, it is not possible to make conclusions about how children made sense of their experiences and what they included in their stories separately from their parents. Additionally, the literature that included children, used a sample of older children and there is a clear lack of young children's voice across the literature. With older children there is the possibility of a range of experiences that may impact on their reported memory, e.g. talking with other children who have experienced similar illness or trauma. Some of the authors do recognise this as a limitation, and it can be argued that the reasoning is because younger children are deemed to be unable to recall their hospital experience and provide self-report information. However, more research is needed with families of younger children, as they make up the majority of PICU admissions (Atkins et al., 2012). As recognised by Egberts et al. (2020), Atkins et al., (2012) and Manning et al. (2017) the experiences of children and their families may be very different if the child does not have the language to explore their experiences as they happen.

This review revealed gaps in the literature which considered the experiences of children and their families outside of the medical field, for instance within education. There is a lack of focus on the implications of a CI on a child's experiences at school, despite the focus on a school aged population. Both McKevitt et al. (2018) and Jones et al. (2022) highlight that parents and children faced challenges at school, and further exploration of this is warranted. This would likely have implications for the EP who is well positioned to facilitate the support across the medical and educational systems. Similarly, there is a gap in how early CI is understood by teachers, who work directly with school aged survivors of CI.

The current research intends to provide a unique contribution to the research base by including stories told by the children, their parents and their teachers. The aim is to gain a better understanding of how those around the child, and the child themselves, come to understand and process their experiences. The research will encourage parents to share their experiences and explore how they construct the impact on their family. Additionally, the current research hopes to focus on children who were of preschool age at the time of their illness or injury to add to the literature focused on younger children. It is hypothesised that for younger children, parents will play an integral role to helping the child understand their experiences and the way this occurs will be explored.

## 2.9 Research Question

1) What are the stories told by young children, their parents, and their teachers about their early childhood illness?

# Chapter Three: Methodology

## 3.1 Overview of the Chapter

This chapter provides an overview of the design and methodology used in the current research. The chapter will firstly outline the ontological and epistemological position and underlying assumptions which have shaped the research. It will then explore the research purpose. In light of the researcher's philosophical position, the rationale for a qualitative research methodology using narrative analysis is then discussed. Finally the research process is described including participant recruitment, data collection, data analysis and ethical considerations.

## 3.2 Ontological and Epistemological Position

A researcher's values impact on how and what knowledge is gathered. Therefore, it is important that researchers reflect upon, and are explicit about, their ontological and epistemological position in order to carry out effective and transparent research (Mertens, 2007).

Ontological and epistemological paradigms relate to the beliefs individuals have about the world. Ontology is concerned with knowledge and poses questions about the "the nature of reality" (Mertens, 2007, p.215) and whether an objective reality truly exists. One can conceptualise ontology along a continuum from realism to relativism. Realism suggests that there is a true reality; a measurable truth that exists independently of one's knowledge and perception of the world (Braun & Clarke, 2013). In contrast, a relativist ontology would posit that there is no single reality and instead there are multiple realities, which are shaped by the way one acquires and interprets the world around them (Creswell & Poth, 2018). Critical realism sits between these two ontologies with the view that a reality does exist, however, this reality is complex and is highly subjective to each individual. Critical realists acknowledge that individuals ascribe meaning to experiences based on their own perceptions and this cannot be fully known or measured (Braun & Clarke, 2013).

The ontological stance adopted will influence the epistemological approach to the research. Epistemology refers to the nature of knowledge and how it is created, understood and communicated (Braun & Clarke, 2013). Two polarised epistemological positions are described as positivism and constructivism. Positivism, which is aligned with a realist ontology, is commonly associated with quantative research in which tangible measures of human experience are created and used to generate and test hypotheses. A researcher with a positivist view is likely to take the role of an observer in which controls are imposed to ensure the researcher does not influence the subject, or vice versa (Guba & Lincoln, 1994). A positivist view fails to address the influence of social, political, cultural and historic influences that impact on how people experience phenomenon.

In contrast, a social constructivist epistemology, aligned with a relativist view, would argue that there are multiple knowledges, and one's knowledge is created through the context and systems within which we exist. Social constructivists believe that all knowledge is subjective and seek to understand individual human experiences. Social constructivism stems from constructivism with more of an emphasis on how language and social interactions construct reality (Andrews, 2012). This view suggests that people can make meaning of the same phenomenon or experience in different ways as we are influenced by social, cultural and historic factors (Braun & Clarke, 2013).

The researcher believed that it was important to take a social constructivist approach when conducting research within the medical field as doctors and other medical professionals hold a position of power (Lupton, 2003). As Foucault (2002) argues, the language used by people in positions of power can influence one's understanding of a phenomena. The medical narrative around illness and recovery shared by medical professionals, who may be viewed to have knowledge and hold power, likely influenced the way that the individuals construct and understand their experiences. The information given to parents during their child's illness and time in hospital may have influenced how they come to understand and remember the experience. With the obvious caveat that it is impossible to separate out parent and professional language when talking about events in the past, the researcher considered it important to keep in mind the language surrounding the illness.  It was possible that the information shared by professionals, influenced how parents made sense of their experiences and was evident in the stories they shared during the research.

One aspect of the current research explores how young children, aged under two at the time, construct and make sense of their world following a serious illness. It is unlikely that the children would have been able to create a coherent understanding of their illness at the time, therefore their understanding is constructed within the interactions between themselves and others. The researcher hoped to gain insight into the children's worlds by studying the 'meanings' they construct through their language and interactions (Ollerenshaw & Creswell, 2002).

### *3.2.1 Researcher's Position*

The researcher's philosophical position influenced all aspects of the current research, including not only the methodology and data analysis approaches adopted, but also which papers were included in the literature review. The current research aims to explore the subjective individual experiences of participants and gain an understanding of how they attribute meaning to these experiences (Creswell & Creswell, 2018). Therefore, the researcher aligns closely with a relativist approach and a social constructivist epistemology. The research is underpinned by a critical realist ontology as the researcher acknowledges that the children in this study have experienced a 'real' physical illness and that quantifiable and observable measures of illness exist. Through taking a critical realist perspective, the researcher acknowledges that each individual's reality is unique and their understanding and perceptions are equally valid; their subjective experiences are the research focus.

### 3.3 Research Purpose and Aims

Research can have several purposes, including descriptive, exploratory and explanatory (Creswell & Creswell, 2018). The current research adopts an exploratory approach in which the purpose is to understand more about a topic or phenomenon. In this case, the purpose is to add to the research base that informs our understanding of how children who have spent time in hospital with CI make sense of their experience.

The literature review identified that there is a gap in the research base regarding an in-depth exploration of the perspective of both young children and their families experiencing a CI. The current research hopes to provide a deeper understanding of how these experiences can impact on a child and their family. Additionally, it will consider childhood illness in the context of education, which will hopefully inform professional practice.

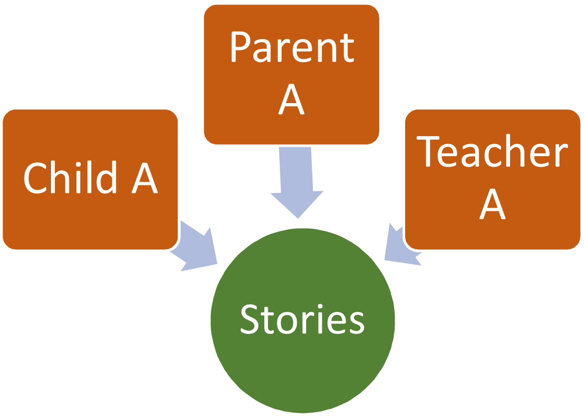
### 3.4 Research Design

The current research adopts a qualitative research design using a narrative approach to data collection and analysis. The research aims to explore the way participants ascribe meaning to their experiences in order to deepen our understanding of a specific phenomenon (Kornbluh, 2015). Qualitative research can be described as an “exploratory open ended and organic” (Braun and Clarke, 2013, p.21) approach.

The research design had a three-part approach to data collection (see Figure 3). From the outset of the study, the researcher hoped to engage children directly and explore their accounts of illness, as well as that of their parents. In addition, by speaking with their teachers, the researcher intends to develop a more holistic view of the child and their experiences by gaining an understanding of how the child and their illness is understood at school. The researcher postulated that this approach would provide rich qualitative data to answer the RQ. This approach also provided an opportunity for the researcher to explore the influence that parents and professionals have on a child's identity and understanding of their experiences. The three stages will be discussed further in the data collection section 3.7.

**Figure 3**

*Data Collection Structure*



### *3.4.1. Alternative Methods Considered*

Several qualitative methodologies were considered during research design and the researcher decided that two were particularly suited to the aims of the study: Interpretative Phenomenological Analysis (IPA) and Narrative Analysis. IPA aims to understand the experience of participants related to a lived phenomenon (Creswell & Creswell, 2018). It is often used with qualitative research as it allows for data to be collected through interviews and other qualitative means. IPA can be used to explore the perception of significant life experiences and could have been used to explore a period of illness. However, IPA does not clarify the impact of socio-cultural context (Braun & Clarke, 2013), which is an integral part of the current research. In addition, IPA requires a homogenous group of participants to ensure there are not too many differences, which might impact on the data analysis (Braun & Clarke, 2013). The researcher was interested in the individual stories of children and their families who had spent time in hospital, and anticipated that there would be variety amongst the nature and context of their illness. Therefore IPA did not seem to be the best fit methodology for this research.

### *3.4.2 Rationale for a Narrative Approach*

The researcher believes that individuals “both construct their worlds and are constructed by their worlds” (Kincheloe, 2004, p. xii). In line with this view, they wanted to focus on the participants’ social and cultural context to understand how they interpret their experiences (Bruner, 1991). Narrative is considered a methodological and analytical approach which seeks to understand individuals’ lived experiences in context (Lewis, 2014). Therefore, in line with the researcher’s ontological and epistemological position, narrative was deemed the most appropriate approach. It allowed for the researcher to explore how people make sense of the world through their stories, which reveal truths about human experiences (Riessman, 2008).

## 3.5 Narrative Approach

Narrative is a broad term which has various definitions and meanings across sociological, psychological and anthropological disciplines (Bamberg, 2011). Within narrative research, there are a wide variety of approaches and methods which can be used (Nasheeda et al., 2019; Riessman, 2008). While a number of different definitions of ‘narrative’ exist, there is a consensus that the term ‘narrative’ is used synonymously with ‘story’ (Kramp, 2004; Riessman, 2008). Story-telling is well established in cultures across the world through fiction and fable, but also in personal anecdotes and autobiographies.

In research, the telling of one’s narrative is a dynamic interaction whereby the researcher participates in the creation of the story (Riessman, 2008). ‘Narrative’ can be distinguished from other qualitative approaches as there is a focus on chronological sequence (Nasheeda et al., 2019). As Carr (1986) notes, human beings do not experience events as independent of one another, thus the process of storytelling usually involves an individual connecting of events into a sequence that is consequential and conveys meaning (Czarniawska, 2004; Riessman, 2008). As people share their stories, they engage in a process of reflection and organisation of their memories to give meaning and structure to their experiences (McAlpine, 2006).

Riessman (2008) argues that the process of recalling memories provides individuals with an opportunity to make sense of their memories, which may have felt fragmented and confusing. This a key component of the current research in which participants were asked to recall and reflect on their experiences. As a result, their memories and emotions associated with their experiences were captured.

Narrative aligns with a social constructivist approach as the process of creating a narrative is influenced by our interactions and relationships with others and the world around us. As Dewey (1963) argued “an experience is always what it is because of a transaction taking place between an individual and what, at the time, constitutes his environment” (p.43). Therefore, one can argue that an individual’s narrative symbolises their view of the world and their reality. Bruner (1991) suggests that narratives are one of our primary tools for understanding human experience, as narratives are used to transmit knowledge and cultural rules through generations, such as typical family structures and traditions. Narratives also highlight the language used and the meaning ascribed to experiences within a particular context (Crossley, 2000).

Narrative is also a therapeutic approach which draws on the idea that the way we speak about ourselves can influence our behaviour and view of the world. Individuals create identity through storytelling, so the language one chooses to use to describe themselves and their experiences offers insight into how that person sees themselves and their position in the social world (Riessman, 2008). Although the current research is not a therapeutic piece of work, due to the topic, the researcher anticipated that having an opportunity to reflect on their child’s illness would hold therapeutic value for parents as storytelling is used to restore order following disruption in one’s life (Becker, 1997). Research identified in the literature review highlights that creating and sharing a narrative was a very important part of the recovery process for participants (Atkins et al, 2012; 2020, Manning et al., 2017). Further discussion of the ethical implications will be discussed in section 3.11.

### *3.5.1 Narrative Research with Children*

Engel (2005) highlights that the focus on children’s narratives has grown in recent decades due to the interest in how children use scripts to make sense of their daily lives. McAdams (1993) suggests that children’s understanding and the way they make connections between people and events is highly influenced by the stories told within their families. Therefore, the stories that young children are told, and tell about themselves, are one of the first ways they learn about and share their experiences of the world (Bruner, 1991, McIntosh & Stephens, 2012).

The researcher wanted to involve the voice of the child, irrespective of their age or ability. Booth and Booth (1996) suggests that narrative approaches can be used to access people whose voices are often excluded due to difficulties in ascertaining them in the first place. The researcher drew on Betchley and Falconer’s (2002) work with young people described as having intellectual disability and difficulties with articulating their thoughts and feelings. The authors argue that for individuals are unable to tell their story, their story is told from the perspective of significant others in their lives. The researcher considered that young children may not hold the primary voice in telling their story. The child’s story may be constructed and shaped by others’ understanding of their experiences as a result of their difficulties understanding their illness at the time it happened.

### *3.5.2 Narrative Analysis*

Narrative analysis involves the interpretation of stories within their social and cultural context (Earthy & Cronin, 2008; Riessman, 2008). Through the process of analysis, it is important that the researcher considers why and how the story is constructed. However, there is not one clear consensus on how to do narrative research and analysis as there is for some other qualitative methods (Squire et al., 2008).

Riessman (2008) suggests four approaches within narrative analysis; structural, thematic, dialogic and visual. She notes that these are not definitive, but can be adapted and combined. Therefore, it is up to the researcher to determine which of the narrative approaches best suit the purpose (Squire et al., 2008). The researcher was drawn to narrative for this reason, as it allowed for a wide range of data to be collected, collated and analysed. Although this flexibility may raise issues of validity (Bell, 2002) the research did not intend to produce an objective truth, but hoped to provide a holistic and deep understanding of human experience.

Polkinghorne (1995) distinguishes between two analytical approaches; the analysis of narratives and narrative analysis. In line with the first approach, stories are collected and analysed with the intention of identifying themes and patterns within the stories. When conducting narrative analysis, an individual's experiences and actions are related to each other as they are synthesised into a coherent story (Polkinghorne, 1995). This narrative analysis approach is referred to as 're-storying' (Ollerenshaw & Creswell, 2002) and involves a process of co-construction between the researcher and the interviewee.

Similarly, Lieblich et al (1998) proposed an approach to narrative analysis along two dimensions; holistic versus categorical and content versus form. The first dimension refers to what is being analysed, which can either be the narrative as a whole, or the themes that make up the narrative. Content versus form refers to whether one considers the features of the story or how it is told. Although, Lieblich et al. (1998) suggest that these ideas can be conceptualised as being along a continuum, they can also be used creatively and are not incongruous approaches.

The current research analysed both the story and the themes within it (Ollerenshaw & Creswell, 2002). As Kramp (2004) suggests, through the process of both narrative analysis and analysis of narratives, rich and insightful data can be produced. The researcher drew on both a categorical-content and holistic-content analysis through which they looked at the participants' stories as a whole, and the themes within them. The researcher was interested in what was told as opposed to how it was told.

## 3.6 Recruitment Process

The research adopted a purposive sampling method in which the participants were selected based on the aims of the research (Robson & McCartan, 2016). Creswell and Poth (2018) argues that there is no specific sample size required for narrative analysis, yet a small sample size is considered adequate due to the large amounts of in-depth data collected. The aim of the research was to gain an in-depth understanding of participant experiences, not to generalise the findings to the wider population of children who have spent time in hospital.

### *3.6.1 Participant Criteria*

All of the children who took part had experienced some time in PCC due to CI or injury, prior to starting school. The researcher did not stipulate criteria in relation to the nature of the treatment the child had in hospital or how long it had been since they were in hospital. Child participant criteria was kept broad to aid recruitment and gather a snapshot of the nature of serious hospital admissions in young children. The researcher also hoped to explore the experiences of children in a range of contexts with a range of illnesses, duration, age, family structure and culture.

Criteria included:

- Child experienced a serious illness or an injury and spent time in hospital (e.g. PICU, High Dependency or Critical Care ward)

- Child is now attending nursery or school in either Early Years, Reception or Year 1.

The parents and teachers of the children were also identified to take part.
The researcher's proposed structure can be seen in Figure 3.

### *3.6.2 Recruitment Stages*

Following ethical approval from the University of East London (UEL) (see Appendix C) the researcher started recruitment. Recruitment took place between May 2021 and January 2022. There were several stages to recruitment as seen in Appendix D.

### *3.6.3 Barriers to Recruitment*

The impact of school professionals having limited free time and an increased workload seemed to be the key barriers to recruitment. For example, the researcher had to contact schools on multiple occasions and struggled to make contact with some schools despite continued effort over several months. The researcher was aware that the schools in their LA were experiencing high staff shortages and increased pressures due to Covid-19. Therefore it is likely that taking part, or facilitating participant recruitment, was not a priority. The implications of these barriers to recruitment which will be discussed in a critique of this study.

### *3.6.4 Participant Characteristics*

Following recruitment, four parents, three children and four teachers took part. Participant characteristics can be seen in Table 2 and 3.

**Table 2**

*Child Participant Characteristics*

| **Pseudonym** | **Gender** | **Age at time of study** | **Ethnicity** | **Reason for hospital admission** | **Current educational setting** | **Receiving ongoing care** | **Family set up** |
|---|---|---|---|---|---|---|---|
| Adam | Male | Four years old | Mixed | Prematurity, multiple admission since for colostomy, heart surgery and, ear surgery. | Hearing unit in Mainstream primary school | Regular hospital admissions due to infection. Due to have additional surgeries for colostomy and ear reconstruction. | Lives at home with mother, father and older sister. |
| Ben (did not take part). | Male | Five years old | White British | Brain tumour (15 months old) and post- | Mainstream primary school | Ongoing check-ups including MRI scans. | Lives at home with mother and father. |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | operative chemotherapy. | | | |
| David | Male | Six years old | White Other | Pneumonia (18 months old). | Mainstream primary school | Ongoing check-ups for dysphagia and thickener in drinks. | Lives at home with mother, father and younger sister. |
| Charlie | Male | Five years old | White British | Brain tumour (18 months old) and post-operative chemotherapy. | Mainstream primary school | Ongoing check-ups including MRI scans. | Lives at home with mother, father and older brother. |

**Table 3**

*Adult Participant Characteristics*

| Pseudonym | Role | Gender | Ethnicity |
|---|---|---|---|
| **Alison** | Adam's mother | Female | Mixed |
| **Tracy** | Adam's Teacher | Female | White British |
| **Laura** | Ben's mother | Female | White British |
| **Mark** | Ben's teacher | Male | White British |
| **Rachel** | Charlie's mother | Female | White Other |
| **Sarah** | Charlie's Teacher | Female | White British |
| **Sophie** | David's mother | Female | White British |
| **Mary** | David's teacher | Female | White British |

## 3.7 Data Collection

Data collection took place between November 2021 and February 2022. On the day of meeting, all participants were reminded of the purpose and nature of the research and what their participation would involve. The researcher reminded participants of their right to withdraw or stop at any point. Participants were encouraged to ask any questions and provided additional verbal consent to take part and be recorded either with a Dictaphone or Microsoft Teams. After the interviews finished, the researcher thanked participants for their contribution and either emailed or provided a hard copy of the debrief sheets (see Appendix E and F). The researcher sent a child friendly debrief sheet (see Appendix G) to the children's parents via email for them to look at together. Additional ethical considerations will be addressed further in section 3.11

## 3.8 Adult Participants

The researcher gave the adult participants the option of whether they would like to conduct the interview remotely via Microsoft Teams or in person.
One parent interview took place in a local library and the other three took place via Microsoft Teams. Parent interviews took between 45 minutes to 1 hour 15 minutes. Two teacher interviews took place in schools and the other two took via Microsoft Teams. Teacher interviews took between 10 to 30 minutes.

### *3.8.1. Narrative Interviewing*

The researcher sought a data collection approach which encouraged participants to share their stories as they wished to tell them. Therefore, narrative interviews were considered the most appropriate approach as they offer flexibility (Riessman, 2008). Narrative interviewing involves the researcher adopting a facilitative role to develop an informal and conversational style of interviewing (Denzin & Lincoln, 2005). The researcher is led by the participants and what they choose to share. Earthy & Cronin (2008) suggest that interviews designed to elicit narratives cause a combination of very broad questions with prompts that are used to encourage participants as appropriate.

### *3.8.2 Interviews with Parents*

The researcher primarily asked parents to 'tell me about (child's name)'s period of illness and what has happened since'. It was important that the researcher gave parents time to think and speak uninterrupted. The researcher allowed parents to talk freely, noting what they chose to focus on and what they considered to be the most important parts of their story to share.

The researcher had a range of prompt points to explore with the parent interviewees (see Appendix H). However, the researcher used these sparingly, depending on how much the participants chose to share and whether they struggled to retell their story. The researcher reflected that the exact questions used are not as important as the capacity to engage with participants (Ollerenshaw & Creswell, 2002). The researcher also acknowledged that there is a fine line between letting the participants take the lead and guiding the conversation to be relevant to the RQ.

Throughout the interview, the researcher wrote brief notes to remind them to come back to a point to avoid interrupting the parents' flow and asked questions such as 'can you tell me more about' to encourage participants to expand on their points, which created a rich narrative rather than brief answers.

### *3.8.3 Interviews with Teachers*

The researcher adopted a similar approach to interviewing teachers and initially asked them to 'tell me about (child's name)'. The researcher had a range of prompt questions to structure the conversation if necessary (see Appendix I).

## 3.9 Child Participants

Three out of the four possible child participants took part in the research. Ben's parents did not give consent for him to take part due to concerns about risk to his wellbeing, which will further be considered in the discussion. The researcher collected data from two children in person at their school, without their parents. However, due to rising numbers of Covid-19 cases, one of the parents felt uncomfortable about meeting in person, and therefore the researcher met with their child remotely via Microsoft Teams, with their parent present. The implications of a mixed approach to data collection will be discussed in the discussion. Child sessions took between 20 and 40 minutes.

### *3.9.1 Methodological Considerations when Working with Children*

The children were central to the research and so the researcher hoped to involve the child participants as much as possible. Interviewing young children involves different skills to interviewing adults (Flewitt, 2005). The younger the child, the higher the risk of suggestibility and bias.

The researcher adopted a responsive interviewing approach to the child sessions (Rubin & Rubin, 2005). This approach recognises that the researcher and interviewee generate the story together, as the researcher listens and responds to the participant, adapting their line of enquiry as the story emerges (Rubin & Rubin, 2005). The researcher also reflected that open-ended questions could be difficult for young children to understand, therefore more directive and simple questions were also used to aid their recall and discussion. The researcher reflected on the challenges of balancing the power dynamic between the researcher and interviewee and the need to be highly reflexive, this will be further discussed in section 3.12.

The researcher reflected on the communicative and cognitive abilities of young children and considered that there was a need to use methodologies that are familiar. Traditionally, narratives are shared through spoken language, although art and visual methods have been suggested to represent symbolic language (Coad, 2007; Riessman, 2008).

### *3.9.2 Tools*

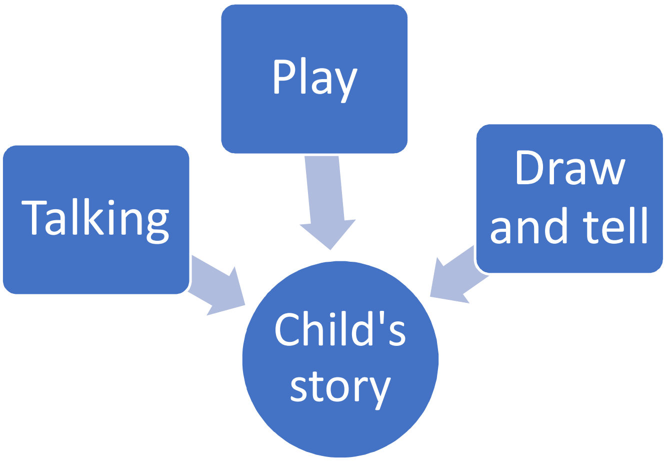
The researcher considered that children's understanding of their illness and time in hospital would be complex. Therefore, the researcher hoped that by providing a concentrated and visual structure to the sessions, the children would find it easier to talk about themselves.

Drawing and play based activities are widely used within the EY and KS1 curriculum, and are familiar to young children attending school in the UK.

Therefore, these approaches were chosen to explore children's experiences in the current research. Drawings were used as a means of exploring the child's sense of self, their emotions and social world (Carter & Ford, 2013). Drawing methods are often used with children where there is an assumption that they may struggle to verbally express their thoughts and feelings (Bagnoli, 2009). The researcher drew on research which has successfully used drawing and visual tools as a way of gathering the views of young children (Bagnoli, 2009; Manning et al., 2017; McIntosh et al., 2012). The researcher adopted a positive, fun and creative way of eliciting the views of the child participant using a range of tools, akin to a Mosaic Approach (Clark, 2017). The different tools to capture the child participants' stories, can be seen in Figure 4.

**Figure 4**

*Data Collection Tools*



Within the 'draw and tell' part of the sessions, the researcher provided drawing materials including paper and coloured pens. The researcher also created a flexible interview schedule with possible topics and activities (see Appendix J) which she used as a guide to structure the conversation. Prepared drawing activities included a self-portrait and creating a timeline. A timeline activity was used to provide a more concentrated visual prompt to encourage the child to reflect on temporal dimensions of past, present and future (Bagnoli, 2009).

In research with children, objects have been used to facilitate communication about their experiences or to elicit their views (Driessnack and Furukawa, 2012). The researcher provided a Playmobil set of a hospital (see Figure 5) which children were invited to play with if they chose to.

**Figure 5**

*Playmobil set*

### *3.9.3 Procedure*

Prior to meeting with the child participants, all children were shown the information letter and an assent form by their parents. The researcher liaised with parents to meet at a time appropriate for the child, either at school, or online. For the one online session, the researcher emailed their parent a link to Microsoft Teams for a pre-arranged time.

During the sessions, the researcher introduced themselves and the structure of the session.  In order to begin developing a rapport with the children, the researcher played a game using a selection of cards from the ‘Therapeutic Treasure Deck of Sentence Completion and Feeling Cards’ (see Appendix K). Once the researcher observed that the child was comfortable in talking together, other activities were introduced and they were offered a choice of what they would like to do first.

During the timeline activity the researcher asked the child to choose what events and information they wanted to put on the timeline. The researcher then asked the child to tell them more about some of the events they had put on their time line.

## 3.10 Data Analysis

Through narrative analysis, the current research hoped to explore the stories told by young children, their parents and their teachers about childhood CI. The researcher chose to apply a narrative framework to help structure the data analysis process (Riessman, 2008). Narrative analysis must be flexible to make sense of the stories being told (Murray, 2015) therefore several approaches were combined. The following section will outline the data analysis stages.

### *3.10.1 Transcription of Interviews*

Following the co-construction of the interviews, they were transcribed verbatim by the researcher. The researcher chose to transcribe the data herself, so she was familiar with the data before the re-storying and analytical process begun. The researcher felt it was important to allow for data immersion. Whilst transcribing the data, the researcher referred to Braun & Clarke’s (2013) notation system. The researcher recorded paralinguistic elements such as laughter or long pauses. Although these were not analysed, they added contextual information to the transcripts which helped with analysis. An example of a transcript can be seen in Appendix L.

### *3.10.2 Storying the Narratives*

This stage of data analysis involved reorganising and re-storying the narratives of all of the participants. Re-storying involves reading and familiarising with the story, analysing and interpreting the story and then retelling this story (Ollerenshaw & Creswell, 2002). The aim of narrative analysis is "keeping a story intact by theorising from the case rather than from component themes across the cases" (Riessman, 2008, p.53). Therefore, the researcher firstly analysed and re-storied each participant's narrative one at a time.

#### *3.10.2.1 Reading and Familiarising*

This stage involved the researcher reading the transcripts and data sources a number of times (six in this case) to familiarise themselves with the content. This stage involves getting "a grasp of the principal elements" of the narrative (Crossley, 2000, p.98). The researcher focused on what the participant chose to include in their story by identifying important concepts, ideas and events within the stories by writing notes on the transcripts (see Appendix M).

#### *3.10.2.1 Re-storying Process*

Through the process of transforming participants' narratives into stories, the researcher brought together the feelings, context and events that shaped their experiences (Polkinghorne, 1995). The interviews did not follow an organised order and therefore the researcher reorganised the transcripts into a chronological order to make better sense of the stories. Whilst reading through the interviews multiple times, the researcher identified excerpts that were related to similar events or experiences and collated these together (see Appendix N for an example).

The researcher then created interim narratives where participants' direct quotes were organised into stanzas (Clandinin & Connelly, 2000). The researcher included the participants’ words as much as possible to represent the unique and distinctive experiences told by the participants (Kramp, 2004). The final step was the re-storying of the participants’ narratives based on the interim narratives (see Appendix O). The researcher re-storied the participants’ narratives with a third person voice to acknowledge the co-construction process and capture the participants’ experiences in an authentic way.

### *3.10.3 Member-checking*

Once the individual stories were created, the researcher shared the final combined story for each child with the parent and the child via email and invited them to speak via the phone or video call. The process of checking the story with the participants allows for ownership of the stories and to ensure that the researcher has co-constructed an accurate portrayal (Ollerenshaw & Creswell, 2002).

### *3.10.4 Identifying Similarities across the Stories*

The second stage of analysis explored the extent of similarities and differences across the storylines. Further details and the ‘Narrative themes’ and ‘Sub-themes’ identified are provided in Chapter 4.

## 3.11 Ethical Considerations

In order to protect the wellbeing of the participants, the research adhered to Code of Human Research Ethics published by the British Psychological Society (BPS, 2018) and the Health and Care Professionals Council ethical guidance (HCPC, 2016). The current research therefore respected the rights of participants and acted with integrity and reflexivity throughout the research process. The researcher liaised regularly with their research supervisor and kept a journal to reflect on their practice and role as a researcher. Ahead of online interviews, the researcher referred to the Association of Educational Psychologists’ (AEP, 2020) guidelines for remote working to ensure an ethical approach to collecting data online. The researcher tried to address any uncomfortable feelings related to meeting via video call and acknowledged this with the participants at the beginning of the interviews.

### *3.11.1 Ethical Approval*

Ethical approval for the current research was obtained from the university ethics committee in March 2021 (see appendix C). The researcher adapted their ethics on two occasions to update the participant criteria and recruitment procedures (see Appendix P and Q). The researcher obtained ethical approval to change the name of the research in March 2022 (See appendix R). The researcher also completed a Covid-19 specific risk assessment related to in-person data collection and subsequently adhered to Covid-19 related guidance. Participant recruitment and data collection only took place once ethical approval had been granted.

### *3.11.2 Data Management*

Personal information was carefully managed and stored to ensure participant confidentiality in accordance with the researcher’s Data Management Plan (DMP, see Appendix S) and General Data Protection Regulation (GDPR) guidance. The researcher produced the DMP ahead of beginning the research and it was approved by UEL in March 2021. The DMP encouraged the researcher to reflect on how participants’ privacy and confidentiality would be respected. Immediately following data collection, all data was transferred and stored on the researcher’s secure university drive. Any original voice or video recordings, on either the Dictaphone or researcher’s computer, were then deleted. The researcher took photographs of the child participants’ drawings and these were also stored on the secure drive. All identifying details discussed in the interviews were omitted or anonymised by the researcher.

### *3.11.3 Informed Consent, Anonymity and Confidentiality*

A copy of the information sheets and consent forms for parents, teachers and children is included in the appendices (Appendix T, U and V). Adult participant information sheets included a clear summary of the research aims and method, their right to withdraw and details of confidentiality and anonymity. The child friendly participant information sheet and assent form used pictorial aids and simple language. All participants were sent the information letters via email and allowed time to consider their involvement and to ask any questions before they provided written consent. Prior to data collection, written consent was obtained from all adults and children. Participants were made aware that any identifying features of persons, settings or LAs discussed in the interviews were omitted or anonymised by the researcher.

### *3.11.4 Wellbeing of Participants and Debrief*

Childhood illness is a sensitive topic to discuss and the researcher acknowledged that participants' wellbeing could be impacted by taking part. To minimise the risk, the researcher made sure that participants understood the nature and purpose of the research and had an opportunity to discuss any concerns. The researcher took an empathetic and attuned approach to interviewing, encouraging participants to speak but acknowledging that they could stop or have a break at any time if they needed. The researcher also drew on their skills as a TEP to identify if participants showed signs of distress and required a break. In addition, the researcher ensured that participants were verbally debriefed after the interviews finished. Debrief letters (See Appendix E, F and G) were also emailed to participants. The debrief letter included the contact details for the researcher and research supervisor, as well as signposting to appropriate support services.

### *3.11.5 Work with Children*

Children, particularly young children, are considered a vulnerable participant group (Robson & McCartan, 2011). Therefore additional considerations were made to ensure the wellbeing of all child participants. The researcher provided evidence of an enhanced Disclosure and Barring Service (DBS) certificate to the ethics board to receive ethical approval for the research. Parents were asked to talk to their children in advance about taking part in the research and ensure they felt confident their child would be willing to take part before a meeting was organised. The researcher also invited a key adult or the child’s parent to stay close by throughout the session.

The researcher acknowledges that for young children, their parents decide whether they take part in the research and that there are issues related to participation. Therefore, the researcher tried to involve the children as much as possible, checking in with them throughout the data collection sessions and offering them choices of what activities they completed. The researcher followed the lead of the children in the sessions, responding in a warm and friendly way to their contributions. The children were invited to take a break or to stop at any point throughout the sessions. The researcher, who is experienced in working with young children, was careful to attune and respond to the children’s signs of distress or disinterest. Following the session, a child friendly debrief sheet was emailed to the child’s parents for dissemination.

### *3.11.6 Ethics of Narrative Approaches*

Narrative research provokes issues related to power dynamics due to the participants’ stories being re-told by the researcher. The researcher tried to address power imbalances by using the conversational style of interviewing, in which the participants were encouraged to take the lead (Riessman, 2008). It was important that the participants were comfortable with the information that they shared. The researcher also member checked the stories before publication and tried to maintain an open and positive dialogue with all participants throughout the research process.

## 3.12 Establishing Reflexivity, Reliability and Trustworthiness

### *3.12.1 Reflexivity*

It is important that the researcher acknowledges that they hold their own personal narratives filled with attitudes, beliefs and views of the world (Clandinin & Connelly, 2000). Particularly with narrative research, the relationship between the researcher and the interviewee has the potential to impact on how their story is created, and therefore it is important for the researcher to be highly reflexive.

There is a need for the researcher to engage in critical self-awareness of how their own views will influence not only the nature of the research, but how they interpret the data. The researcher was careful not to embellish or alter the participants' narratives to suit the research aims.

To reduce the risk of bias, the researcher kept a research diary throughout, particularly during data collection and analysis. The research diary included their reflections, decisions and issues that arose. The researcher hoped that being self-aware of their own bias and keeping a record, would help maintain a transparent data analysis.

### *3.12.2 Reliability*

Although there is less focus on reliability in qualitative research, the researcher still tried to provide a clear account of how the research was conducted. The researcher kept an audit trail of the research timeline (see Appendix W) and kept a record of all paperwork, ethical changes and emails. The researcher became familiar with the interview transcripts and was able to re-listen to the interview recordings to check they were accurate as necessary.

### *3.12.3 Trustworthiness*

To ensure trustworthiness the researcher engaged in member checking by sharing the re-storied scripts with parents. The researcher also kept the stories of the participants close during analysis and examples of participant verbatim were used to justify any interpretations and findings. Especially when working with children, the researcher acknowledged that to correctly interpret the meaning or messages communicated, further checking would be necessary. The researcher engaged in a conversation with the children about any drawings they made, asking them questions to further explore the meaning behind what they had drawn to help ensure an accurate interpretation of the data. To remain true to the child’s narrative, the researcher included the language the child used throughout data analysis and presentation. The researcher anticipated that by allowing children a choice of ways to tell their story (see Figure 4), the data would be more meaningful.

## 3.13 Chapter Summary

This section has outlined the research methods used in the current study. The current research is underpinned by principles of social constructivism which led to the use of a narrative approach and analysis. This chapter provided an outline of the recruitment process, data collection methods and data analysis. The participant stories and research findings will be explored in Chapter 4.

# Chapter 4: Findings

## 4.1 Introduction

As described in Chapter Three, the researcher conducted a narrative analysis to illustrate the unique experiences of participants and also, to identify common themes across their experiences. In this chapter the researcher will present the two stages of analysis. Firstly, the researcher will present the narratives storied in the 're-storying' phase. Then key similarities and differences across the stories will be explored.

## 4.2 Storied Narratives

As identified in Chapter Two, the main aim of this research was to answer the question: *"What are the stories told by young children, their parents, and their teachers about their early childhood illness?"*. Therefore the re-storied narratives are central to this research as they provide insight into the participants' experience of childhood illness.

## 4.3 Charlie's stories

### *4.3.1 Charlie's Story as told by Rachel (Mother).*

Noticed something was wrong

Rachel first noticed something was wrong when Charlie started having spasms and shrieking in pain. Rachel knew straight away that something wasn't right, as children don't usually do that. Charlie didn't have a cold or temperature but Rachel took him to the doctors straight away. It was a Saturday so Rachel took Charlie to the out of hours GP and even on the car journey, he did it a couple more times. The GP recognised that there was nothing to explain the spasms and suggested they go to A&E the next day.

Luckily diagnosis was quick

Rachel feels they were very lucky that the doctors took them seriously. When they were at A&E, a consultant walked past Charlie and noticed his spasms as some sort of seizure. Charlie had a CT scan soon after and they could see something was not right, so he was sent to the specialist hospital. It was a really quick process from symptoms starting to diagnosis, with lots of appointments and visits in the space of two to three weeks. Charlie was diagnosed with a brain tumour in November, just before he turned two. Rachel feels lucky as she had heard horror stories of children taking years to be diagnosed.

### Surgery

Rachel remembers the surgeon positively and hero worshiped him as because of his skill, he managed to get the tumour out without doing any long term damage. The surgeon was very calm and had a great way of talking to the family about the tumour.

The tumour was located in a part of the brain where they wondered if he might lose feeling in one whole side of his body, but, only Charlie's leg was impacted. Due to Charlie's age, his brain elastically is much higher so the surgeons predicted that he would get movement back, which he did. Rachel doesn't feel that the tumour has had any impact on Charlie's personality or memory or anything like that, there were only short-term physical implications.

### In a little bubble

Charlie was in hospital for about a week before his surgery so the doctors could run tests. As Charlie was so young, he didn't know any different. Rachel described Charlie as being in a little bubble in his room where she could occupy and entertain him, so he was mostly fine. Rachel remembers that he barely cried for the entire time except for when had a seizure, as these caused him considerable distress.

### Staying just for physio

Charlie handled the surgery and recovery well. Although because he lost movement in his right leg, Charlie and Rachel had to stay in hospital so they could access physio for half an hour a day. This was frustrating for Rachel as they were confined to one space all day whilst waiting for their physio slot. Rachel felt it was important to get the family back together in time for Christmas and that Charlie would do better in the home environment. The surgeon noticed Charlie playing with his brother Christopher and confirmed that they should go home as being with his brother Christopher is how Charlie's going to learn to walk again. Charlie got to go home a few days later, this was a positive experience for Rachel and the family.

### Getting the call

Rachel remembers getting the call back after they did pathology on the tumour. Unfortunately Charlie's tumour had come back as high grade when they thought it was going to be low grade. As he had a high chance of relapse, Charlie needed to have chemotherapy, which started just before Christmas.

### Chemotherapy was the worst part

Charlie had six months of intense chemotherapy at hospital, so the family spent a lot of time going in and out of hospital for treatment and blood counts. Rachel spent most of the time in hospital with Charlie as she was breastfeeding him so he was very dependent on her. Rachel's husband did two or three nights. Rachel feels that the chemo was worse for Charlie than the surgery, as it made him feel really sick. Charlie had the intense chemotherapy through a Hickmann line, so although it was awful, Rachel found relief that it wasn't their responsibility as parents.

However Rachel and her husband found it very difficult when they had to give Charlie the oral chemotherapy at home. Charlie had a year of oral chemotherapy at home on monthly cycles with regular blood tests to check he was ok to continue treatment. It was a horrible experience and they used to dread going through that cycle each month as Charlie hated taking the medicine.

### Important to be together

Throughout Charlie's brain tumour and treatment, it was important for the family that they were together. Rachel's priority was always being at home and it was her gut instinct that this was the best place to be. When Charlie was in hospital, at weekends Christopher came down and they would spend time together.

When the family couldn’t get home, they would go to one of the home from homes and spend time together there, they tried to be together as much as possible that way.

It drove Rachel mad when they were asked to travel to another city and then wait a day before the chemo could start, as it felt like a day was lost. Particularly when the family didn’t know whether the prognosis was going to be good or bad, they felt like they were wasting time that could be spent together. Charlie was never really really ill because of the chemotherapy and he wasn’t bed bound. So it was their priority as a family to go out and do activities, it was important to try and get through things.

### Support and communication were key

There were times when the support from hospital was frustrating for the family. Although Rachel felt the surgery was handled well, when Charlie was at home, the hospital wouldn’t arrange physio so the family had to pay for it themselves initially.

Rachel felt that when the family received the news about the grade of the tumour it all went a bit downhill. Rachel felt the transition from surgical after care to oncology, which meant being shared care between two hospitals, meant that the communication was horrendous and they had mixed messages. Rachel didn’t feel very supported as an outpatient because there was no one to help you in helping your child to take the chemotherapy medicine. The family lost confidence in the team at this point.

### Lack of trust in the team

Charlie’s oncology consultant was open about their lack of knowledge about the tumour and refused to look beyond the standard of care. Rachel pushed for a change in consultant so they could pursue the testing recommended by doctors in America who had expertise in Charlie’s tumour type. The testing meant they identified a mutation and were prepared if the cancer came back. This experience made it difficult for the family to trust the team as they had to advocate and felt pressure to do the right research.

During the peak of Charlie's illness, Rachel wanted to be informed and did a lot of research. Charlie had a rare tumour type and she wanted to find out more about it to give her a feeling of control back. Based on her research, Rachel can see that in America there is a very different health care system but there's much more acknowledgement of the after effects of treatment than she experienced in the UK.

### Charity was a life line

Rachel felt that the support from charity services was a life line for the family in terms of the emotional side of it. The charities also supported Rachel with organisation. The nurses helped when there was poor communication, for example when they weren't sending blood tests and things. Rachel could just text the charity nurse and she would relay the messages and sort it out. The charity also paid for the physio that Charlie needed to help him walk again. Rachel felt that the support meant that Charlie and the family could carry on with their routine, which was important. To save the family from going to hospital every other day for blood tests, the nurses visited Charlie at home and even at his childminder.

### Being around other families

Through the charities, the family went to fun days where lots of children were going through chemo so had visible signs of illness. Rachel found it supportive to know they weren't alone and for Charlie to see other children that look like him. Being around other people going through similar journeys was supportive because they didn't have to explicitly talk about it but just being together was good.

### Family dynamic changed

Rachel and her husband's relationship definitely suffered during the illness, but now they have come out the other side stronger. Rachel has a new sense of perspective following the brain tumour regarding the little stresses in life.

### Perfect storm for Christopher

Looking back, Rachel feels that the biggest impact has been on Christopher because he understood how worrying it was and potentially fed off his parents' worry. Charlie's age was important as she thinks it had less of an impact on him than his brother, who was four years old when Charlie became unwell. Whereas, it was the perfect storm for Christopher, as he was just starting school and everything changed for him during those formative years.

Rachel felt it was important to be open and not hide things from Christopher. After Charlie's surgery, Christopher visited him on the oncology ward where he made friends with some children who were also not very well. Rachel feels this was a strange experience for him. Because of his age, Christopher was aware of how serious it was and in some ways, he entered that 'world' more than Charlie did.

Before Charlie had a brain tumour, the family were very close and Rachel and her husband were always at home. The children were not used to them being away so it was a big change when she had to suddenly go to hospital with Charlie. Rachel wonders whether Christopher has separation anxiety because Rachel had to be away a lot with Charlie when he was unwell. Christopher has experienced periods of anger and has had lots of questions. She wonders whether Christopher likes to control things now because he lost so much control over his life when his brother was in hospital. Christopher's whole life was affected, he didn't get to have his birthday party as Charlie couldn't get out of hospital. There were lots of things that had a direct impact on Christopher that didn't for Charlie because of his age. The family have just started paying for Christopher to see a Cognitive Behavioural Therapist.

Gaps in support

Rachel feels there is a gap in support that acknowledges the impact of childhood cancer on siblings as they are on the journey too and they can get left behind. Rachel also feels that there is absolutely no support out there for children who have been seriously unwell, as if their physical recover is enough. Although she is grateful that Charlie has recovered, she felt bad asking for help to kind of process it all. Rachel felt it would have been helpful just to have an appointment where professionals could ask “what would be most useful?” as she had to follow things up herself, like when Charlie needed a hearing test. Rachel wonders whether it would be helpful for Charlie to have someone to talk to about his experience, and acknowledge, that “yes this happened to you”.

### Long-lasting effects

#### Struggling to sleep

Before the operation Charlie slept fine. However, straight after the surgery, he started struggling to fall asleep. Rachel described it like a switch, and even if he is exhausted he will not switch off. After the surgery, Charlie was constantly awake in the night and didn’t seem tired. Rachel wonders whether something was knocked in the surgery, like the part of the brain that helps you go to sleep.

Charlie started chemotherapy within a couple of weeks of surgery, so it’s hard to know what part, if any, of Charlie’s treatment impacted on his sleep. A nurse recommended melatonin and this helps Charlie as he is able to fall asleep naturally. Rachel reflected that she had forgotten to mention his sleep as it is just such a normal part of their routine now. Charlie has some other health implications such as being prone to chest infections, but he is mostly fine. The family were a bit cautious with Covid, but the doctor said there is no need to isolate as he is off chemo treatment.

#### He’s a grazer

Charlie lost his appetite during chemotherapy and it was important to keep his weight up. The family tried lots of different foods and wanted to make sure h ate. Charlie is a bit of a grazer now, he wouldn’t sit down to have a full meal because he’s used to his parents constantly trying to give him food, but they were not worried about setting up bad habits at the time.

#### Aversion to medication

One of the longer lasting impacts which Rachel noticed coming out the other side, was Charlie’s aversion to medication. Charlie will take capsules now, but it took a long time as he associated them with tasting disgusting and he recognised that medication would make him feel really ill.

### Scans are the worst part

The scans have been the most difficult part for Charlie as he didn't like when they had to use needles and find a vein. When Charlie turned five, the consultant explained that if he could lie still for forty minute, he wouldn't need the injection. Rachel gave Charlie the choice about whether he had the anaesthetic and went to sleep or not as she felt he was old enough to make a choice. Rachel had had an MRI scan in the past and found it incredibly claustrophobic but Charlie seems fine. He understands the importance of the scan to make sure that the tumour is not back and he can stay still for these. Charlie is proud of the fact he can lie still for the MRI scan, he talks to everyone at school about it.

### Charlie now

Rachel described Charlie as a cheeky, confident and normally hyperactive child. He has a great sense of humour and definitely has his own mind. He is very laid back and takes things in his stride. At a recent parents evening, Charlie's current teacher was very positive about him which is amazing and talked about how confident and chatty he is.

### He gets a grip of himself

Charlie will physically get a grip of himself when he his nervous about something, and can be determined that he is just going to do it. Rachel thinks this because he remembers going through things that he didn't like, such as fingerpick blood tests, but he knew he had to do it. Charlie seems to have taken the attitude that you might as well do it rather than stressing about it, which Rachel feels is a bit sad as this is because he has been made to do so many things he didn't want to. However, she recognises this is a good survival mechanism for life.

### Occupying himself

There have been some other positive things that Rachel has noticed, for example, Charlie is really amazing at occupying himself. Her husband wonders if this is because Charlie was in hospital for long periods of time so this was inadvertently how he was brought up for a couple of years, instead of running around like a typical toddler.

### Worried she missed something

Rachel worries whether she has missed something. She has read and seen all of the things that make you think there are going to be long term effects. She was worried about his speech and he had an assessment, but Charlie's speech developed and he is fine now.

### Settling into school

Charlie settled into school fine, he did a few half days at first. He had some really strong friendships that he made in preschool which meant he was relaxed starting school. Rachel feels that Charlie is confident talking to adults as from such a young age, all sorts of adults were invading his space. Therefore talking to a teacher doesn't faze him. Rachel wanted the school to treat Charlie like any other child. Charlie's reception teacher was ultra-emotional and because she had taught Christopher, was aware of what was going on for the family. Rachel wanted the school to be quite strict with Charlie and not let him get away with things.

### School are supportive

The school have been really supportive of Charlie and the family. Charlie goes to a small school so the staff are kind of aware of what the family have been through. It's good because if Charlie brings it up when it's relevant, the teachers know how to support him and have conversations about it. They can talk to the other children about it too. Charlie told his mum that recently at school another girl had not believed him when he said he had survived cancer. Although he didn't seem upset, Rachel shared that he was mostly annoyed she didn't believe him.

### Important that children understand what is happening

As Rachel and her husband are both teachers, they recognised the importance of children understanding what is happening so they've always been honest.

Rachel wondered if she probably went too far the other way by trying to explain what was happening. At Charlie's age, he wouldn't have understood words like chemotherapy. Rachel explained to him that the doctors took the tumour out which is amazing because it all came out in one piece. She tried to explain that he had to take the medicine to make sure the tumour doesn't grow back. Rachel had to explain the effects of the medicine because there were physical visible side effects such as his hair falling out and feeling really sick.

Rachel wants Charlie to talk about it as much as he wants to because it's a huge part of him and who he is. As they don't know what the future holds, it is important Charlie is aware of what happened, although she doesn't want it to be the centre of all conversations. She hopes Charlie can find the balance as he grows up.

### Changing with age

As Charlie gets older, Rachel feels he is beginning to question things more and realise that the scans are serious. After his most recent scan, Charlie seemed relived for the first time when his parents told him the scan was clear as he is beginning to understand what that means. Rachel worries he is going to suddenly freak out about how ill he was and start to worry about it coming back. Rachel described that Charlie will bring it up quite a bit during random conversations and she feels it's obviously on his mind. Charlie will sometimes make a joke if someone says they are unwell, he will say that "it can't be as bad as when I had my brain tumour". Rachel wants to make sure she supports Charlie in the right way so that he doesn't get really worried. She doesn't want Charlie to ever say he can't do something because he had a brain tumour.

### Processing death

Unfortunately last summer a friend of the family's daughter passed away from a leukaemia relapse. The two families had been on the journey together. Rachel tried to be really honest with the boys as she felt they needed to understand. The little girl was in Christopher's class so a nurse from Clic Sergeant went into school to speak to him specifically because he was really worried that the same thing was going to happen to Charlie. Charlie was part of these conversations too but he didn't have the same questions as Christopher.

Religion

The family are not religious but both Charlie and Christopher have shown an interest in religion. Charlie has recently became hooked on Hinduism and what it means. He has enjoyed the stories about the different gods and festivals and wants to find out loads about them. He wants to cook Hindu meals and has been asking a friend of Rachel's about Hinduism. Charlie will say he is "the only Hindu in the family" which can be amusing but comes from a more serious place.

Rachel feels this is Charlie's way of processing things and that Hinduism is something he has decided helps him not to be worried about dying. Charlie is coming to terms with what happened and wants to be at peace with what he believes. Whereas Christopher has had lots of deep questions about religion and asked whether it was God's choice that Charlie had a brain tumour. After his friend with leukaemia had a relapse, he had lots of deep questions which has shaped his view today.

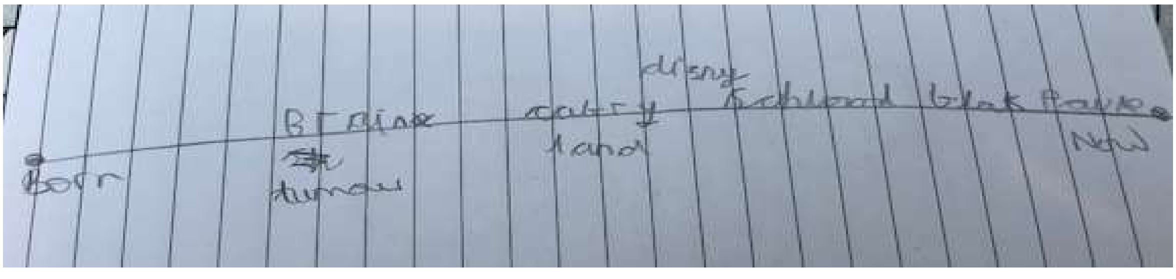
### 4.3.2 Charlie's Story

My brain tumour

Charlie's brain tumour is one of the important events in his life. Charlie thinks that surviving a brain tumour makes him unique and special.

**Figure 6**

*Charlie's Timeline*



### I’m a survivor

Charlie shared that he doesn’t think about his brain tumour anymore. However, he likes talking about it because he is really proud that he survived it.

### Diagnosis

Charlie knows that he was born and then he had his brain tumour when he was one. Charlie knows that before they realised he had a brain tumour, he was brushing his teeth and he kept stopping. He knows that his hand was moving in an open and closed way. He knows this because his mum told him about it a few months ago.

### Memories of hospital

Charlie doesn’t remember much of being in hospital but he remembers bits. Charlie remembers going to the hospitals with his dad and his dad pointed out the room where the Dr took out the brain tumour. Charlie then remembered the room, he thinks it was the orange or the yellow room.

### Recovering

Charlie remembers that after the surgery, he had to learn to walk again. Charlie’s brother Christopher was jumping around and because he wanted to jump with him, Charlie started to walk again. Charlie remembers walking to his dad. Charlie is not sure how old he was when he started walking again, but he checked with mum who told him it was when he was 2.

### Horrible medicine

Charlie’s hair fell out and he thinks this is because his brain tumour was affecting his head. His mum reminded him that it was because of the medicine. He remembers that his eyebrows fell off too. Charlie remembers the medicine was horrible and his brother used to make him take it. He wonders whether the medicine was a type of poison.

### Going back to hospital

Charlie has been back to the hospital a few times for a scan and he knows it is to check if the tumour is coming back. Charlie can wait for six months now until he has his next scan. Charlie remembers staying in the hospital for a bit after one of the scans and then going to Cadbury land. Charlie has been on a few other trips, one of these was to Disneyland. Charlie remembers a difficult time was when he was in hospital and he had to have a needle in him, which he didn't like. He remembers that when they took them off it really hurt, so he prefers to do the scan without the needles. Now, he has to lie really still when he has his scans. The scans are really loud and he puts a CD on to listen to instead but he can't really hear it anyway.

**Figure 7**

*Charlie's Star Award*

### Celebrating beating cancer

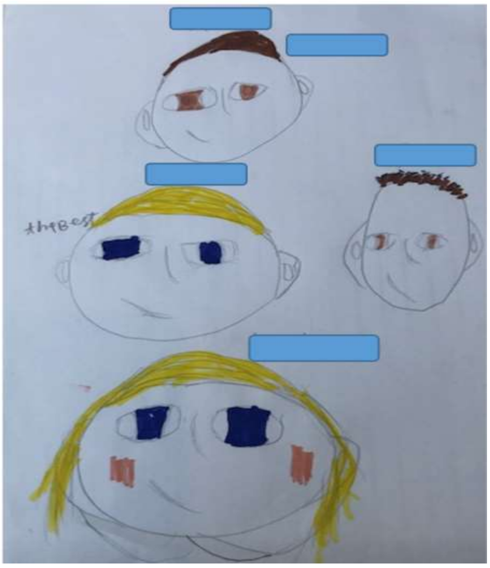
Charlie has lots of items to celebrate his beating cancer. He is most proud of his star trophy which he got for his brain tumour from 'Cancer Research UK Kids and Teens'.  Charlie also has lots of beads which he got for having different procedures.

Whatâ€™s important to me

Charlie’s favourite colour is white and his favourite animal is a cat. He has a cat called Poppy. Charlie also likes monkeys and elephants. Charlie enjoys drawing with his friends and likes to draw a lot of different things. Going to school and being with his friends is an important part of Charlie’s life. When Charlie started in Reception he was separated from his best friends because they have different surnames and the classes were organised alphabetically. His family are very important to him and he is happiest when he is with his family and they are happy – it makes him smile. When Charlie grows up he wants to be a footballer.

**Figure 8**

*Charlie’s Self-portrait*



### *4.3.3 Charlie’s Story as told by Sarah (Teacher)*

Feeling lucky to work with him

Sarah feels lucky to have worked with Charlie since he was in Reception. At school, Sarah describe Charlie as a sociable member of the class. She shared that Charlie is a happy go lucky child, who is full of joy and always smiling. He loves to have a joke and seems to really enjoy the social aspect of school and has some really secure friendships. Charlie doesn't cause any problems at school. Charlie behaves beautifully and always makes the right choices, he is a good role model.

Sarah described that Charlie appears quiet, but confident, and he definitely knows what's going on. When he's questioned about something, he has great knowledge. Charlie doesn't need to be at the forefront of attention and he doesn't often put himself out there. Sarah described that Charlie is likely in the background getting on with what he has been asked to do.

### Parents have helped him

Sarah believes that Charlie's parents have done a brilliant job of supporting him and giving him the skills to process and talk about what he's been through. Rachel has been fabulous and they have a brilliant working relationships where they will chat about whatever is needed.

### All staff are aware of what Charlie has gone through

As Sarah worked with Charlie in Reception, she knew what was going on for him. When Charlie first joined the school, the staff were sure to be aware of any illnesses that were going around and communicated with mum and dad about Charlie's immune system. Sarah shared that this monitoring has followed him through school although they are not as wary now. The staff communicate with mum about COVID-19 to make sure she was comfortable with him attending. All staff were made aware of what Charlie had gone through.

### Charlie talking about the brain tumour

At school, Charlie is fabulous about talking about what he has been through in a very open and calm way. He is able to articulate what happened and is happy talking in front of the class. Sarah lost her mum before Christmas to cancer and had told the class about this. Charlie said to Sarah that he had a brain tumour when he was little and told the class about what happened. Charlie then said that he was lucky enough to survive. Charlie is in a very supportive class and his peers will say to him that they are so lucky that you're still here.

Charlie talks about the facts a lot and uses the right terminology. Sarah reflected that it must be hard because he was so young when it happened. She thinks that because Charlie has come through it, he can look back and think about his brain tumour as a part of him. When Charlie talks about his experience it can be a shock as an adult because he is so articulate and calm about it. It seems that Charlie needs to talk about his experiences.

## 4.4 Adam's stories

### *4.4.1 Adam's Story as told by Alison (Mother).*

#### Something was wrong

Alison found out she had a twin pregnancy early on, but at 13 weeks, she had a really heavy bleed and thought she'd had a miscarriage. However a scan showed that there was still a heartbeat - this was Adam. At the 20 week scan, they told Alison the baby was fine, but in her mind it wasn't done correctly. In her mind - something was wrong. Alison didn't feel well so she went for a private scan where she was told that her water levels were really low and she needed to go to hospital straight away. Alison then had regular scans every two weeks up until Adam was born. At the last scan, at 33 weeks, they said that she needed to go into hospital straight away so they could deliver the baby.

#### First breath may be his last

Alison was supposed to have a natural birth but she had to have an emergency C-section. Alison was told that the Adam's first breath may be his last, because there was no fluid around the brain so his lungs hadn't developed properly. Alison wasn't sure what to expect, she assumed everything except for the lungs would be fine.

When he was delivered, Adam was taken away from her and put on a ventilator.  Alison was shown a picture, but she couldn't be with Adam straight away because she had a C-section. Alison's husband and best friend were at the hospital and they went to see Adam. Adam was covered with a towel and he had a hat so they couldn't see what he looked like.

### Diagnosis

A few days after birth, Alison was told that Adam had a condition called Microtia which usually means children have hearing loss. This was scary for Alison as a mother as she panicked and worried that he was going to be deaf. It was the first thing she asked, but they couldn't check his hearing because his ears were so small. Alison had a feeling he was deaf because they were in a noisy neonatal unit and he wasn't responding to any kind of sound.

Alison and Adam were then transferred to a specialist hospital. Here, Alison found out that Adam had additional complications, including issues with passing urine and three holes in his heart. Initially she was told he had some sort of heart condition which was incurable, but it turns out they were wrong. This was a very difficult time as Alison had to adjust to finding out she had a baby with multiple medical issues.

### "I can't do this".

Alison remembers that she didn't know what to expect regarding Adam's ears, she thought they would just be small because he was premature. Alison remembers staying at the hospital house close by and she was absolutely exhausted as she wasn't sleeping or eating properly. She was going back and forth to the hospital all the time. She remembers that her husband stepped in and said she needed to rest so he went to the hospital to spend time with Adam.

At this point, they had taken Adam off of the ventilator for the first time and he had no hat on, so it was the first time anyone had seen his head properly. Alison remembers her husband called her to warn her about Adam's ears.

When Alison got the hospital she was so shocked she walked out and said "I can't do this".

### Realising it didn't matter

Alison remembers that she called her mum and shared her worries about how people were going to look at him and laugh– she worried how she would deal with this. Alison's mum said to her, "do you love him?" and Alison realised it didn't matter what he looked like because she did love him so she went back upstairs straight away. Alison remembers that she had sent her husband a message saying that she can't do it which he showed her the other day, although she laughed about it, Alison remembers this day like it was yesterday.

### Hardest thing as a mother

Adam's illness was the hardest thing Alison has ever had to go through in her entire life. Nothing will ever take over the feeling of not knowing whether Adam was going to live or die. Alison feels it more as a mother because she made Adam and he grew inside of her. She worries that she did something wrong and it was her fault.

### Coming to terms with not knowing

The downsides of Adam's condition is still the not knowing. Alison had to come to terms that she may never have the answers as to why this happened but it will play on Alison's mind forever. She doesn't know whether it's a genetic reason, and she wonders if you went back hundreds of years, there might be something in the family history. Alison signed up to a genetic testing but she doesn't want to know now as it might take 20 years to find out anything. She doesn't want to sit around worrying every day that someone going to call her, especially as there is nothing they can do to change it now.

### Blame

Although Alison can't fault the NHS, she blamed them for not realising Adam has all of his health problems when she was pregnant. Sometimes she wants to scream at the NHS. Alison behaved in a way that she never thought she would because as a mother, she wanted answers. She was annoyed that they didn’t pick up on the holes in his heart in the scan, as they should have seen those. At one point, Alison went to the clinic where she was scanned and told people not to get scanned there.

### Surgeries

Once at home, Adam was booked to have open heart surgery which was successful. Adam was only 6 pounds 2 when he had the surgery which was nerve wracking for Alison. Adam also had surgery to fit a bone anchored hearing aid which and has to wear a soft band around his head because he doesn’t have an ear on one side. Even though he was diagnosed with severe hearing loss, Alison didn’t think that Adam needed the hearing aid at first, as at home, he responded to loud noises so she didn’t always make him wear it. A while later, when Adam was almost two, Adam had an operation to fit a colostomy bag. He has had many surgeries to try and rectify the difficulties with passing urine and stools.

### Supportive staff

Alison has had a really positive experience with all of the medical staff. Adam is under two hospitals’ care because he his urology complications are quite rare. Alison has a closer relationship with one of the hospitals because the urologist has done Adam’s operations since birth. Whereas, the other hospital is quite professional and she has hardly met the doctors there. The hospital secretaries are amazing and Alison can call them whenever she needs something.

### Coming to terms with it

Allison used to cover Adams’ ears when they went out, by putting a hat on him and covering him with a blanket so no one would look at him. She also used to put tape on his ear to hold his ear lobe back. Alison felt quite insecure about what people would say and think. Adam has short hair now so his ears are on show. Alison can’t remember how long it took for her to adapt to Adam and other people’s views, but it didn’t happen straight away. However Alison has no regrets now. She often used to think if someone told her that Adam would have these conditions, what difference would it have made? It wouldn't have made any difference and she would have still gone through with the pregnancy. Thinking about it in this way is helpful.

### Dealing with other peoples' stereotypes

There have been two occasions where other children haven't been very nice to Adam. Once was in a shop where a little boy asked why Adam was wearing his band on his head. When Alison said because he can't hear you, the boy asked whether it was because he was stupid. Alison found this difficult, but assumed he said that because of the stereotypes about being deaf and dumb. Alison had to explain that he isn't stupid and he can talk if he gets to know you. Alison thinks this sort of thing goes over Adam's head but it's very hard for her to hear. Alison tries not to react because she doesn't want Adam to think there's something wrong but she did go home and cry about it because it's horrible to see someone ask that about her little boy.

### Ups and downs

Alison is a strong character but she wasn't always in the beginning. Although she has come a long way, she is not positive all the time. At times, Alison has lost it a bit. She suffered with depression after Adam was born and although she didn't need any medication, it was a difficult time. Alison was very protective of Adam as a baby and wouldn't let anyone hold him, not even his dad. Alison still has days when she gets emotional. Sometimes things get to her and she cries because her little boy has had to cope with so much.

### Playing on her mind

Alison recently told her sister to make sure they check the ears in her pregnancy scan, which made her sister paranoid. Alison reflected that this probably means things are on her mind more than she thinks they are. Alison finds it hard when people moan about little things like having a bad night's sleep. Although she knows everyone has their own things, it's still hard and Alison wishes they would be quiet.

### Ways of coping - Being informed

Alison has always wanted to know everything about her son's condition. When Adam first went home, Alison remembers crying because she wanted to know if he was deaf, so she could be prepared to provide for her son and know what she needs to learn to look after him. The health centre contacted the hospital who did an audiology assessment and confirmed he had severe hearing loss in both ears.

### Being grateful

Allison worried that Adam wouldn't walk or meet his milestones like other kid, but he has. She was worried Adam wouldn't speak as his speech was delayed, but he does. Adam does everything she would wish for. Adam is here and she is just grateful. Alison reflects that she's lucky to have a family. Seeing her children the way they are, Alison has no choice but to be positive.

Alison isn't religious but someone said to her that 'God would never give you anything you can't handle' and she has held this with her. She feels she has two choices, she can either give up and her kids will feel it or she's got to get on with it. Even when it is hard every day, she has learnt to adapt because there is no choice.

### Perspective taking

Alison finds it inspiring to see other parents with their children. When she is at the hospital she has seen parents pushing their children in wheelchairs and communicating with them in ways that she didn't think was possible. When the children smile with their mums, Alison realises that it's not as bad as she thought and it helped her to move on.

Alison's sister was premature and her mum reminded her that she was fine and that was 40 years ago. This helped Alison realise that Adam has the potential to be ok. Alison also thinks about if Adam was born in another country, he wouldn't be here today, and that helps her realise how lucky she is.

### Other families

Alison met a lot of people through her time in hospital but they don't stay in touch as much as they could do. The families would see each other go through surgeries and pacing the hospital with their new-borns. They kind of reassured each other and when Alison saw children older than Adam who have been through surgeries, it was helpful to hear their stories of when they were young.

Alison was part of a Microtia group where she met a parent with a child two weeks older than Adam. They used to see each other in hospital when they were small. Alison and the family do a lot in terms of Microtia fun days, she did a fun day run with her daughter where they raised money for the charity. Alison found the support groups helpful in the beginning but she doesn't need that anymore because Adam sees deaf children in school.

### Family - Supportive family

Family is the most important thing for Alison. Alison's mum is her best friend, they speak all the time and she has been a great source of support throughout.

Alison's husband was definitely the stronger one at times, especially at the beginning when Alison couldn't deal with certain things. He was able to be brave, or at least put a on a brave face for her. He has been by Alison's side through every surgery. When Alison was really struggling with the uncertainty and wanted to scream at the NHS for taking so long, Alison's husband supported her and reminder her that they needed to concentrate on their son. Over time, Alison feels they have come a long way as a family.

### Adam's sister

Adam has an older sister who was seven when he was born. It was heart breaking for her when Adam was born as she wasn't allowed to visit him in the ICU and she was so excited to have a baby brother. Alison shared that her daughter has been so strong throughout the whole situation. Alison expected her to turn around and say "everything always about Adam" but she hasn't thrown that at her. She has always carried on, even when she had to miss her birthday party because Adam's surgery had complications.

### Everything is normal now

Alison feels everything is normal now, Adam and his sister love each other and fight like cat and dog. They'll play, cry and shout - just like a normal household. Alison has done exactly the same things with Adam as she did with her daughter. They do a lot together as a family. Sometimes when Adam is driving Alison bonkers, she looks at him and it just feels so normal. It shocks Alison as she can almost forget what they're going through, because although she doesn't like the word, Adam will never be normal.

### No more children

Alison won't even think about having another child as she is petrified of the thought of going through this again. This is quite sad for her as she always wanted a big family, although she is happy she has a girl and a boy.

### Impact on Alison's life

Alison has had a few problems at work in terms of them not supporting her through her pregnancy. When she told them she was ill, they said that pregnancy wasn't an illness. Alison didn't go back to work until Adam was over a year old and initially she did evenings as she went to work when Adam went to sleep. She currently works part time in school hours.

### Sleeping

Adam initially slept in his own room but around 18 months old, became more alert about what was going on. At this point, Alison had to start sleeping next to him. Adam won't sleep well because he can't wear his hearing aid to bed. Adam finds this quite scary because he can't hear anything. Alison tries to explain that no one can hear at night as they are sleeping, but Adam gets upset. Alison still has to sleep next to Adam. If Alison goes downstairs when Adam is asleep, he will wake up so Alison has to stay with him all night.

Adam won't go to sleep until Alison is there either, so she can't do much in the evenings. Alison doesn't have much of a social life, but she doesn't mind too much. Alison's friends will come over or she will go to theirs with the kids, or meet in the day. Most of her friends are parents now so they get it. Alison's husband sleeps on the sofa, which causes some relationship problems at times.

### Starting school- Happy to take him on

Adam went to nursery before school. Alison found the staff really supportive and they were fully aware of Adam's needs. Alison didn't have any problems with any of the nursery staff. Adam was the first child they had with disabilities but they adapted really well to it and were happy to take him on. They never said that they found it difficult after Alison showed them how to change the bag. Alison keeps in touch with one of the staff from nursery as Adam liked her so much.

### He is behind

Adam is about a year and half to two years behind where he should be in terms of numbers and letters. Adam doesn't always recognise them and he can do some things backwards. Alison wondered if it was because he was dyslexic, but it's probably more because he missed out on so much of his early stages of life. The staff at school explained to Alison that when babies crawl they are learning. Adam was in hospital for most of his early life so he did not get to explore his environment in the same way.

### Settling at school

Adam settled into school instantly and there were no problems. Alison was really worried and they did a settling in week, but he wanted to go all day early on. He goes to a mainstream school with a hearing impaired unit. Alison believes Adam is the only one at school with Microtia but there are lots of other deaf children. There are lots of different children with different needs at his school so Alison feels it is the best school for him. The school are really supportive and Alison calls them every day without fail for one reason or another. They are always willing to talk to her and let her know how things are going on.

### EHCP

Adam has an EHCP. Alison found this process straight forward. She had heard stories about how it can take years, but because Adam's was medical grounds, it was quite easy and black and white.

### Adam is happy and tough

Alison described Adam as a really happy, friendly, affectionate and chatty little boy. He loves going to school. He likes to play with the girls at school and he's into softer play. Alison believes Adam is really tough as he has already overcome so much more in his little life than most people do in their whole life.

### Going to hospital is normal

Going to hospital is normal for Adam and he is very used to it. Adam will let the doctors do all the checks in the world and not bat an eyelid. Alison shared that when an Educational Psychologist visited Adam at school, he didn't quite get that she just wanted to talk, as he is so used to professionals wanting to look at him.

### Still has check ups

Although Adam has not had any surgery for a couple of years, he has to go to hospital for regular check-ups for his heart, his hearing and his colostomy bag. Adam often has to be anaesthetised because the check-ups can be quite invasive. Adam has been anaesthetised maybe thirteen times now which is quite a lot. Alison finds it really hard to see Adam like that as he is really groggy afterwards. She wants to make sure any future surgeries are spread out.

Adam suffers with urine infections all the time and has had to miss a lot of school as a result. Alison has got used to this now, and takes him to A&E when she can't get his fever down. The staff at hospital know him and know what to do and he now takes daily antibiotics.

Adam is still under review from the dietician because he was born so underweight and because of his heart condition he had to be tube fed. He doesn’t eat much now and cannot eat after 5 o’ clock otherwise he will get a really upset tummy at night.

### Upcoming surgeries

They are hoping that Adam will get to have his colostomy reversed in the future. Alison is waiting for a letter to come through with dates. If Adam has the reverse colostomy, they will have to potty train him again which will be really strange for everyone. The school will be really hands on with that to help and support. Adam is also due to have an implant fitted soon so that the hearing aids will be connected by two magnets on the back of the skull. Alison is excited about the surgery which is new to the UK and means he won’t have to wear his BAHA anymore. Without the BAHA you wouldn’t even notice his ears.

### Adam is becoming aware

Now that Adam is a bit older, he is becoming aware. Alison has explained to the hospitals that’s why she wants them to do the surgeries for his colostomy and hearing aid now. Adam has started asking questions about his body like “why are my ears small mummy?” or “why do I have this mark on my chest?” Alison reckons that Adam asks her questions at least twice a week. Alison tries to explain that we’re all different - we all have different colour eyes, hair and skin. But now he is four, Adam wants to know why he is different to his friends. Adam could have reconstructive surgery when he is 8 years old. Alison wants Adam to come to her and tell her that he wants that done, she doesn’t think it is her decision to make.

Adam will talk about his hearing aid as his ‘magic ears’ and that without them he can’t hear. Each morning Adam will take his BAHA from the end of his bed, put in the batteries and put it on. He can do this by himself now. He then takes it off at night.

Adam doesn’t really understand about his heart condition. Alison tried to explain that because there was a hole, they had to fix it and make it better using cello tape. Adam will tell people that he has cello tape on his heart.

Adam thinks that having his colostomy is normal as he doesn't really see other children going to the toilet, he just thinks that's what everyone does. Adam knows he has a special bag. When Alison told him they might be taking it away as part of his surgery, he got really upset because he sees it as them taking a way something that is his. Adam was under 2 when he had it fitted so he doesn't know any different.

### Talking to Adam about his conditions

Some people have told Alison she should tell him more, but she thinks Adam is too young. If she sat him down and said "you've got Microtia" he wouldn't get it. One day Alison will have that conversation with him. Alison doesn't want to hide what has happened but because Adam is only four, and doesn't fully understand, there's no way that she can explain it all to him properly. There will be an age for that, Alison still sees Adam as her baby and she's not ready for that yet.

Alison told Adam that when he goes for his implant surgery the magic doctors are going to give him some magic medicine so that he goes to sleep and that mummy will stay with him the whole time. She told him that when he wakes up, he's going to have magic ears which will be amazing and you can go running and hear music that no one else can.

### Adam doesn't remember much

Alison doesn't think Adam remembers much of his time in hospital but sometimes seems to remember specific details from his hospital visits two years ago. Alison has pictures from his times in hospital. Adam enjoys looking at pictures of when he was born and Alison shows him pictures of when the tubes were coming out of him. Adam sometimes laughs and says "why am I wearing a pink split on my arm - I'm a boy!" There was a song that she used to sing to Adam as a baby. Adam remembers it as the 'baby song' and asks Alison to sing it with him every day.

Worries about the future

Alison will worry every day for the rest of her life about Adam. He will always have heart complications and always be deaf, there is no surgery in the world that can fix that. Alison thinks about whether Adam's children would have the same conditions. She worries about him having children and thinks she shouldn't really worry about that as he's only 4. Allison worries about Adam getting bullied and it will have a big impact on his life. Primary school will be ok because he will be with the same children but when Adam goes into the bigger world, kids aren't very nice. Adam will need to learn to be strong when he goes to secondary school.

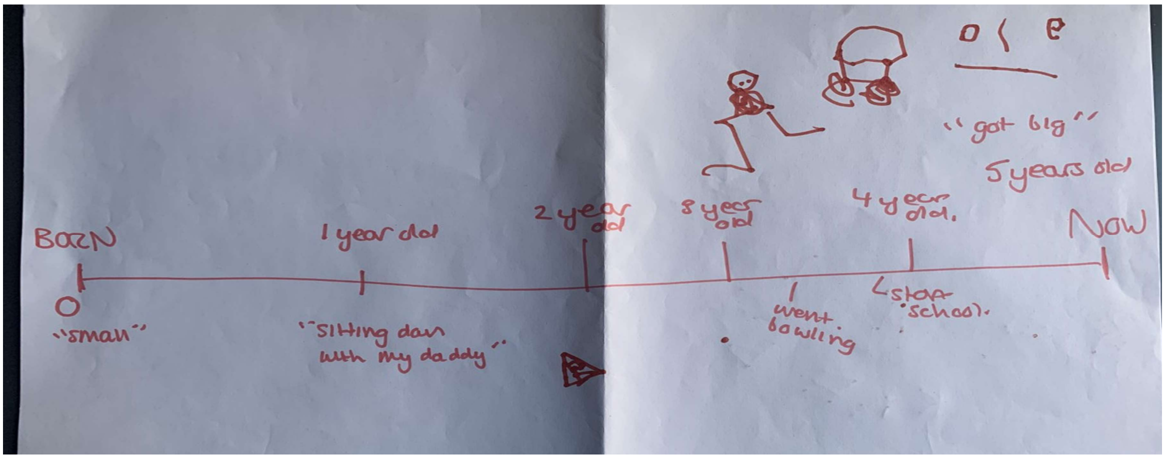
### 4.4.2 Adam's story

#### Adam's life

Adam thinks he was small when he was a baby. When Adam was 1, he was little and at home. He used to sit down with his daddy and they had Man United t-shirts on. When Adam turned 4, he got lots of presents for his birthday and started school. Now that Adam is 5, he has gotten big. When Adam got big, he got to go bowling.

**Figure 9**

*Adam's timeline*



### Adam’s favourite things

Adam’s favourite people are his mummy and daddy. At home, he likes to play with his paw patrol toys. Adam’s favourite animal is a dog and he loves to watch paw patrol on TV.

**Figure 10**

*Adam’s self-portrait*

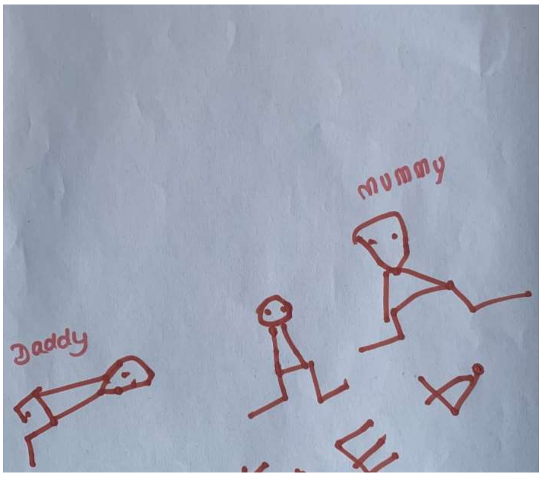


**Figure 11**

*Adam’s Play Mobil Set*

Adam played with the play Mobil set and commented on what he was doing. Adam remembers that when he went to hospital, he was pushed in a chair and taken to a room to have an operation. When Adam was in hospital, he stayed in the bed. Adam remembers that they would check his heartbeat afterwards using a stethoscope. Adam thinks that people in hospital are sad because they are at hospital.

Adam also put the split on the child figure a few times, but didn't comment on this.

Adams understanding of his hearing aid

Adam remembers that he has been to the doctors to check his hearing. Adam knows that he has a headband so that he can hear and he is going to have an operation to give him a new hearing aid.

### *4.4.3 Adam's story as told by Tracy (teacher).*

Adam doesn't stand out in the class

Adam started at school in the hearing impaired resource base. At school, Tracy described Adam as a very happy and confident little boy. Although he was a bit shy when he started, which was funny because Alison shared that he is usually so outgoing. Adam is doing really well socially, he is very popular and has lots of friends. Adam presents as a typically developed child and he doesn't stand out in the class. Although Adam needs to feel very sure before he will contribute something as he doesn't like to risk being wrong. Tracy wonders if Adam's social skills and outgoing nature can sometimes mask his language deficit.

Impact of his condition

Tracy feels that his medical issues have had an impact on Adam. She believes Adam comes across as a child who has missed a lot of incidental learning, partly through his deafness, but mostly from being in hospital and not being able to explore his environment. In terms of his learning, Tracy feels the main issue is his literacy as it can be a challenge teaching children a system based on sounds if they didn't hear well during that critical period for language learning. Staff use the visual phonics system with Adam to give him clues about the place and manner of articulation. Adam appear to have some issues with working memory particularly auditory working memory which also impacts on his learning.

Tracy shared that although Adam was significantly behind when he started, he is now on track to meet his early learning goals. Tracy is not concerned about Adam's speech in the long term, he just has some humps to get over to catch up.

### Adam fits in

Tracy shared that Adam has never experienced social exclusion because all children learn to sign at school. Adam also isn't the only one at school with medical needs and staff try to normalize it as much as possible so that there isn't any stigma or embarrassment around it. Tracy reflected that children can be unkind further up the school.

## Support

### Zoom calls with the hospital

Tracy has felt really supported and informed by the hospital and they have been brilliant. Tracy had zoom calls with the hospital to talk about Adam's care needs before he even started school. Tracy reflected that the specialist children's hospital are better at understanding the impact of attachment. The staff were really informative and available, which isn't always the case with health staff.

### Supportive family

Tracy believes that Adam has an incredibly rich learning environment at home which has helped him. Alison is so on the ball too and willing to go the extra mile for him. She will come into school and show staff how to do things whenever they want her to. Tracy shared that Alison pushed for the urology nurse to come into school too.

### School knowledge of his conditions

Adam had more of an induction than other children but it wasn't entirely necessary and he settled really well. The school were not sure how much deaf awareness there had been at his old preschool, although he had the same speech and language therapist who supported the transition.

Tracy has a good understanding of Adam's medical needs and his BAHA and how it works. She knows that Adam is due to have surgery to insert the hearing aids inside his skull soon so he can have a much more stable hearing aid. Adam is very good at moving his band if it slips, but the new implants will be much better as Adam is an active boy and won't have to worry about the implants moving. Tracy is aware that Alison is hopeful that the toileting issues with be reversed soon and Adam will be toilet trained.

### Talking with Adam about his condition

Tracy wonders whether the uncertainty about having his surgery is difficult for Adam. Adam recently came back to school after having the preparation for surgery which was then cancelled. School and home had done a lot of work with him on what it would be like not having to wear his band anymore. When Tracy told Adam she was sorry he hadn't had the operation, he turned away from her which he doesn't usually do. Adam usually blossoms with adult attention and he seemed dysregulated by the experience.

Tracy feels that Adam doesn't have the language to process his experiences in a way so staff have played a lot with dolls with colostomies and head bands and explain it to him in simple terms. Staff try to ensure that his routine is clear, and everyone is aware of his needs so that he has consistency. When staff bring it up, Adam will talk factually about his colostomy and what it means for him.

Adam and the staff don't talk about any emotions related to his experiences and Tracy wonders if Adam probably doesn't have the language yet. Adam doesn't seem to get upset when they talk about it, but he doesn't particularly want to talk about it. Tracy wonders if this is just because he doesn't really understand, but he never spontaneously brings it up.

## 4.5 Ben's stories

### *4.5.1 Ben's story as told by Laura (mother).*

Something was wrong

Laura noticed something was wrong on Ben's first birthday when he woke up and had been sick. At first she thought it was something to do with having his first piece of cake, but unfortunately it turned out to be a bit more sinister. Over the next few months Ben had ups and downs with normal childhood illnesses like ear aches and temperatures. Ben was Laura's second child, so she was a bit more relaxed. There was an incident when Ben woke up and he was sick and couldn't move his neck properly. Laura found this really worrying and had lots and lots of trips to A&E with no resolution.

One day, when Ben was 15 months, Laura woke up and didn't know what to do. As a mum, she felt really scared because all of the tricks in the toolbox like cuddles or calpol were not working. She told Tom she was going to take Ben to the GP and hoped he has a good answer for her.At the GP, the Doctor said that Ben looked happy enough but Laura couldn't get out of the chair and go home. She felt that they had to do something. The doctor suggested she went to A&E, and although Laura had been many times, she went back again.

It didn't feel right

This time, they agreed to do an MRI scan. Laura remembers that the MRI scan went on and on and on. Although Laura hadn't been in an MRI before, she thought it didn't feel right. Whilst waiting for the results of the scan, Laura remembers feeling awful as she didn't know what was happening. Laura thought there couldn't be anything wrong as staff had spoken to her and given her a meal.

### "Ben's got a brain tumour"

A doctor then told Laura to sit down and said "Ben's got a brain tumour, he needs to go to Children Hospital now so we can operate and take it out". Laura remembers appreciating how clearly she communicated the news. She also found that in the moment, being in a professional mode was a helpful coping mechanism, as she sort of took herself out of the situation of being a mum.

Ben and Laura travelled to Children Hospital that night. They waited until morning to have the operation so the surgeons could have a night's sleep first. The next morning, Ben had an 8 hour surgery to completely remove the tumour.

### Relief

The doctors warned Laura that he might wake up and not have much function so they would have to wait and see. Laura remembers that she was eating a banana when Ben woke up and he reached out to grab it. This was a huge relief for Laura and she looked at Ben and thought 'you're going to be alright'. Ben spent a few days on intensive care and then was sent home.

### Chemotherapy was absolutely hideous

Laura remembers being called back once they had a bit more of an understanding of the tumour and what the next few months would look like. The doctors explained that it was a medulla blastoma tumour. Although Ben was completely free of the tumour, he needed 9 months of chemotherapy to make sure no residual parts of the tumour had gone into his spinal fluid or the rest of the brain. Laura remembers the doctors telling her that they were going to make Ben, who at the time looked really well, look really ill.

Laura remembers that the chemotherapy treatment was absolutely hideous, especially for a baby who needed his nappy changed every hour of the night because it filled up with chemo. Ben's gut and throat lining came out and he was screaming in pain a lot of the time and wasn't able to eat. Ben had a Hickman line in his chest for a few months because he needed so many blood transfusions. Ben had weekly admissions to hospital in between chemo treatments because he was so unwell. After the treatment Ben had MRIs every 3 months and lot of blood transfusions for the first year because he was still very unwell. Ben found it hard to get back to an even keel after that.

### Josh's diagnosis

Two months into the hellish experience of Ben's chemotherapy, his older brother Josh was diagnosed with cancer. This was awful for the family and Laura wasn't sure how she was going to manage it. Laura and Tom had to balance both boys' treatments. Josh's treatment was in America so they had to split their time between America and England, flying back and forwards at the weekend.

### 'Grumpy potato'

Laura reflected that it was hard to know what Ben thought about his illness because as soon as he started treatment, he turned into what they used to call a 'grumpy potato'. Laura described that Ben was deadpan and that he seemed to go right into himself as a protective mode. Ben didn't laugh or want to be entertained and they couldn't cajole him. Laura described that it as if someone had paused him and he had disassociated from what was going on. Under the surface, Laura feels that Ben was working hard just to be. Although, he was quite lively with Josh. When Josh became ill, the attention Ben received was halved and that was very hard for him. Laura remembers that the day Josh got sick, Ben went more into himself and didn't come out of himself for a very long time.

### Schedules finished on the same day

After a few months of chemo, both boys schedules finished on the same day at the same time. Laura remembers that they walked out of the hospital holding hands together and it was a really amazing sight to see that Ben had the support of his brother all the way through. The boys had baldheads together, they were sick together and they had central lines in their chests together. Ben and Josh shared more than most brothers ever will.

### Support on offer

When Laura has spoken to other families, they have told her that they got support from different people. Laura can't remember what it was like for her family. She reflected that it might not be that the support wasn't there, but that she didn't take it up. She is quite an independent person and professionals have told her that she's too independent. Laura found a lot of professionals being involved quite invasive because their lives were so out there. The family were always in hospital and always had people in their home. Community nurses came to the house to change the dressing and check the line, but once that was removed, they didn't have as much support for Ben at home.

### Needed all sort of support

The family needed all sorts of support. Laura didn't know what was in her fridge for two years, let alone if she had made it or not. There was always someone on their doorstop and some friends were willing to just turn up at the drop of a hat to help with whatever difficult thing cancer threw at them.

### Support was overwhelming

Laura and Tom were inundated with stuff so they had friends who coordinated it and got the family what they needed week by week. The support was sometimes overwhelming and Laura found that at times, she wanted it to stop. There were things arriving at their house all day long, maybe three to four packages a day. The admin involved in dealing with even the recycling was too much and Laura didn't have the headspace at the time. Laura reflected that realising how lovely people were was as emotional as the things they were going through.

### Way of coping

As a way of coping, Laura and Tom wrote a blog and they took turns to write it week by week. Writing the blog was a way of making sense of the process and to communicate with family and friends. Laura finds it is amazing to be able to read it back now as sometimes she wonders what the hell happened because the whole experience was so insane. The blog was a shared view and it helped Laura and Tom to build a positive narrative during a really despairing time. The way they wrote the blog guided how they were feeling.

### Best and worst of times

Looking back, the experience was the best of times and the worst of times for Laura and Tom. They spent more time with the boys than they would have otherwise if they had been working. The intensity and connection they had with Ben and Josh was insane. Tom feels he has had this amazing chance at fatherhood that a lot of people don’t get where he really has been there in every sense of the way. Ben has equal attachments to both Laura and Tom due to their closeness.

### Stepping out of the ordinary and into the extraordinary

The family got to experience many wonderful things in between the awful experiences, like going for a drive in a Lamborghini after proton treatment. Laura felt that when they got the diagnoses, they stepped out of the ordinary and into the extraordinary - they lived an extraordinary life.

### Never normal again

Then one day, it all stopped and they had to pretend to be normal again. Laura described it as wearing a mask because she never felt normal again after the mind-blowing experiences they had.

The experience changed Laura. She feels she is less of a people pleaser which is a good thing as she used to find that really tricky. Laura had to wear new shoes. She became an advocate for her children when she previously may have said “oh no don’t worry”. Laura realised how strong she can be and that she can be a leader when she had always thought she was a quiet and unassuming person.

## Ben’s experience

### 0 to 100

Laura feels that Ben has struggled with his emotional regulation over the years and he can be 0 to 100. After he was diagnosed, it was very hard to comfort Ben. He would scream for hours and push Laura away if she tried to comfort him. Over time, Ben has accepted more and more comfort.

### Drawing to make sense of the world

As Ben’s language improved, he developed a really amazing emotional vocabulary and can talk about what’s going on for him. Most of the time, he draws what’s going on for him and has his drawings are absolutely incredible. He uses the drawing to explain his experiences. Ben can share how he’s feeling, how he makes sense of the world and how he connects with his family and feels safe when he is not with them.

### Talking about it

Laura doesn’t always know what Ben knows about his experiences. When it comes to talking about it, she always follows his lead. It is hard to know his take on it as it comes out in bits and bobs and at very unusual times she will suddenly get a question about something.  Laura shared an example from a few months ago when Ben asked Laura some questions about his brain tumour during bath time. Laura remembered that he asked her “how did they get this thing out of my head?” “What was the thing my head? What did it look like?”. When Laura said she didn’t know, Ben closed his eyes as if he was pretending to go through some pictures. Ben then said that he saw it and he knows what it looked like. Laura described that it is as if he is either pretending to remember or he goes back to something, but she doesn't know what.

### His experiences are so mixed up with Josh's experiences

Laura reflected that it is hard to know how much Ben understands as his experiences are so mixed up with Josh's experiences. Laura thinks Ben's understanding of his illness will come with time. If Josh hadn't passed away they might have talked about it a bit more but it hasn't felt appropriate to go over and over it. Laura reflected that trying to remember the details can be difficult as Ben and Josh's treatments blur into one.

### Fascinated by pictures

Ben likes to look at pictures of the time when he was ill because they are often with Josh. Laura recalls that there are some crazy pictures. There is one of the two boys running around with bandages on their head, no clothes on and their central lines hanging out. It is quite an unusual picture and Ben is fascinated by it and asks questions about what was on his body.

### Josh's death

Josh died at home when Ben was almost 3. Ben was able to say goodbye and saw his brother be collected by the funeral director. The family were supported by the community nurse who helped the family at this time. Ben was at Josh's funeral and was very involved. The family designed lots of things around the funeral like asking people to write to Ben with a memory of Josh. They have hundreds and hundreds of postcards addressed to Ben. Laura tried to include Ben at an age appropriate level.

### Medicine doesn't always work

One thing that is really hard for Ben to understand is why his medicine worked and Josh's didn't. As a result, Ben is very fearful of people being ill and their medicine not working. He is also fearful of blood so if he cuts his finger he can't look at it. When Josh died, they had to explain that sometimes people are really unlucky and their medicine doesn't work or doctors don't have the right medicine. They have to reassure him that most of the time doctors do have the right medicine. But Laura reflects that she can’t reassure him that they always will. This is hard for Laura as she has to be honest with him but also be gentle.

### Nursey was overwhelming

Ben attended nursery before he was unwell. He didn’t go back for a long time but then started a couple of mornings a week when he was on the mend. He attended for about a year but it wasn’t particularly successful as whilst he was there, Josh died. Ben seemed to find it overwhelming and he said there were “too many toys to play with”. Laura feels that the staff were also overwhelmed by Josh’s death. Laura felt it was a bit uncontained and unhinged so they decided to move Ben to the school nursery.

Ben was quiet for a long time when he started at the school nursery but he wasn’t in distress. The staff said to Laura that they were not sure if anything is going in because he is so quiet and serious. At that time, he was quite self-directed, probably more than other children his age. He was also quite resistant to talk to anyone.

### Coming back to life

When coronavirus started, Ben attended nursery with a small group and had a good time. Laura thinks being back at home with his parents for a while and having that consistency was also good. Ben seemed to find the demands of life quite hard so it was nice to have no demands at home. Over time, Ben’ seemed to be enjoying things more and coming more back to life.

### Ben now

Laura described Ben as a quirky, funny and popular boy. He doesn’t always want the attention but when Laura sees him in the playground, other children are always trying to say hi to him. Ben doesn’t seem to need the attention. Ben can also be a deep thinker and quite introspective. He spends vast amount of times on his own and isn’t bothered. He can be very involved in his lego or drawing or playing with his teddies. However, he does really love company when he wants it and he gets on well with people. He's a very healthy robust boy now and doesn't get too many coughs and colds.

### Need in all areas

Laura has attended lectures of acquired brain injuries and this was very scary. There are poor outcomes for children who have those sorts of intervention when they're young and there are all these things that can happen. Laura thinks that Ben really fits the profile of having a bit of need in all areas.

### Impact of tumour – nature vs nurture

It's hard to know whether his tumor has affected his gross motor skills. He took a long time to walk, and he can't ride a bike. When he is swimming, it is as if his brain is telling him to do something and his limbs can't do it. It is hard to know that is in effect of the brain tumor, or just because he is a more cerebral child who likes to sit down. He was sitting down a lot during his illness. But he doesn't run around much, and he doesn't often want to play games like football. Laura takes Ben to football club, but mostly for the social element. It's hard to know what aspects of Ben are nature vs nurture.

### Impact of chemotherapy treatment

Laura thinks the chemotherapy treatment affected Ben's processing. He is quite a slow processor and he needs lots of time. Sometimes he will tell Laura about something that happened weeks before. If she asks Ben what he thought of something after an experience he often can't tell her. The chemotherapy effected Ben's ability to talk, which Laura read can happen with chemotherapy. Ben used to do something which Laura had never seen a child do before, where he would pretend to talk by moving his mouth but no noise would come out. Ben definitely wanted to talk but it just didn't come out.

The chemotherapy also definitely affected the ability to feel safe eating because he was weaning whilst having chemo so he felt really sick. Ben still has a very basic diet consisting of fresh and salty food, which is basically what he had when he was having chemotherapy. Laura can see that he really wants to try things that finds it really physically challenging and he feels proud of himself when he tries something new.

Laura thinks that the chemotherapy definitely affected Ben's sensory needs. Ben finds the hustle and bustle of school overwhelming and is often exhausted at the end of the day. Ben didn't sleep well for years because he had been woken up every hour for a long time. Sometimes he would wake up at 2am and then wouldn't go back to sleep. Ben gets 10 hours sleep a night now but that has only been in the past 6 months. Laura thinks this is probably the first time in his life he has had that much sleep and probably has a lot to do with how good he is functioning now.

### We make a pretty good team

Laura and Tom struggle with having an only child and get very fearful whenever Ben is ill. Tom sometimes doesn't worry about things as much as Laura but she feels that she cannot 'unknow' what she knows.

Laura thinks they make a pretty good team as they are relaxed and pushy about different things and although they have their moments, they generally have a good balance. Tom was amazing when the boys were ill as he gave up his job because Laura's was more flexible at the time. Tom was the primary carer. Laura remembers that was interesting as when she would arrive at the hospital they would direct information towards her despite Tom being there for days.

### Challenging for everyone

Laura reflected that situations like Ben's can be challenging for everyone, not just the parents. The family's local GP misdiagnosed both of the boys and unfortunately was also the GP who came to sign Josh's death certificate. Laura and Tom have had long conversations with him about how they don't hold him responsible because it's not something you see all the time.

### Revisiting trauma

Laura reflected that they could have been more involved in the hospital but they don't really want to because it feels like revisiting trauma. They may have gone back more if Josh hadn't died, because it I was such a beautiful place for them as they looked after the boy's very well but they also had some traumatic experiences there.

### Poor communication

When the family have to go to Children Hospital for Ben's check-up scans it can be difficult as the communication across the hospital isn't always pulled together. At Ben's last scan, the anaesthetist asked him if he had any siblings just as he was falling asleep which was unhelpful.

### Ongoing review

Ben will be under review for up to 5 years after his treatment. He has MRIs every 6 months, which are due to go down to once a year but it may be different in Ben's case because of having a brother with cancer can raise the changes of having cancer. Ben is more likely to get a secondary cancer than most people so he is kept on a heavy review.

### Protective factors

Although Laura acknowledges being poorly and in hospital when they're young impacts on children, she also thinks that protective factors can make such a difference. The family have a great support network including amazing neighbours with children who are like cousins to Ben. Working as a psychologist means that Laura can advocate for Ben in a different way. She has the skills to be able to support his play in a different way than other parents might. Although she wonders if she sometimes overthinks it because that is the nature of the job.

### Supportive school

Ben has a brilliant school who really understand him which is another protective factor. The school were good when Josh was diagnosed in Reception and almost treated him as if he was a looked after child by doing things to keep him in mind.

When Ben started school they monitored and spoke to Laura and what was going on. Ben would sometimes get very scared of an image that was innocuous to anyone else, suggesting a bit of trauma suddenly came out. The school were very open to Laura talking about how they can deal with that and they don’t brush it off and take the conversations seriously.

### *4.5.2 Ben’s story as told by Mark (Teacher)*

Ben doesn’t stand out as different

Mark described Ben as a really sweet boy who is really well behaved. He is very chatty and he can be a little bit cheeky. Ben can also be very determined, if he doesn’t want to do something, he will say so. His independence stands out and his previous teacher also said that he would just do what he wants to do. Mark thinks Ben is a great kid who doesn’t stand out as different to any other child. He is just a cheeky little kid who loves school and is really enthusiastic about everything he does.

Friendships

Ben is really popular and has loads of friends. He has some really close friends that are almost lost when he’s not there, whilst Ben is quite independent. Mark used to see Ben playing outside in the reception area on his own doing his own thing. He seems more than happy to be on his own or happy to be with friends.

Deep thinker

Ben is a deep thinker and comes up with answers that Mark hadn’t even thought of. He is very independent and doesn’t necessarily want to use the examples Mark provides, but wants to come up with his own ideas. Mark described that he is not the best listener and has problems with concentration. Marks thinks could be because of his age, or because of what he has been through. He will sometimes stare into space and is a bit of a daydreamer. Ben doesn’t tend to listen fully to instructions and then will go off and do his own thing.

### Wouldn’t have a clue meeting him

Mark knows that his parents were concerned about Ben but he is doing really really well at school. Mark reflected that because Josh died, people could almost forget what Ben has been through as you wouldn’t have a clue meeting him. Despite not always concentrating, Mark noted that he always does a good piece of work. Ability wise, Ben is in the middle pushing towards being above age related expectations in some areas. Mark described Ben’s art as unbelievable and he loves to draw. Ben can be very modest, Mark had to really prompt him for him to recognise that his drawings as one of the things he is good at.

### Ben is stable

Mark described that he hasn’t really seen Ben get upset or annoyed about anything but he can get a little grumpy. Considering what he’s been through, Mark thinks he’s really stable. He is impressed with the way that Ben copes with things and he is regulated in his behaviours and his emotions. Mark tries to treat Ben the same as everyone else - he tells him off and praises him like everyone else and he knows that Laura and Tom have tried to treat him as a regular kid.

### Talking about his brother, Josh

There was a big concern that Ben was so young when everything happened, although Mark thinks it’s good in some regards, because he won’t necessarily remember what he’s been through. However, he still has good memories of his brother who is always going to be a part of his life. The school have a ‘Josh day’ which will continue until Ben leaves the school. Ben reportedly loves this day. When the class do work about families, Ben will mention Josh as if he is still about. He recently drew a picture of his parents and his brother Josh, and talked about him like any normal child would talk about their brother.

Ben has never mentioned his brain tumour

At school, Ben has never mentioned his brain tumour. Although Ben talks about Josh, he has never mentioned what happened in the past. Ben had a scan a couple of weeks ago and his parents shared that he got quiet emotional because apparently it was a bit of a difficult situation with the anaesthetic. When Ben came back to school he didn't show any effects or talk about it. Mark wonders whether he is holding back or whether he genuinely isn't bothered. It can be hard to know. Mark hopes that these experience won't come back and hit him when he is a bit older and understands it more as he is still so young now.

School knowledge of his illness and support

As Mark knows Ben and his family well, he knew what was going on for him. Ben's parents are very strong and the school have always been supportive of the family. All of the staff at school are aware of what Ben had gone through because Josh passed away whilst part of the school. The school don't make a big deal out of it. When Mark passes on his class to the next teacher, he will fill them in with details because they might not know as much.

Ben has always been fine

As far as Mark is aware, Ben has been fine since he started school. Everyone at school is aware of his situation and that Ben could struggle with certain things like memory. Although Mark believes that there wasn't anything put in place in addition to being aware of the situation as when Ben started, he was on the road to recovery.

## 4.6 David's stories

### *4.6.1 David's story as told by Sophie (mother)*

David was always quite a chesty kid and he had his fair share of chest infections. When David was 18 months old, Sophie and her husband had taken David on holiday. When they got back, David was especially chesty.

Sophie thinks that the long flight and lots of swimming meant his chest was particularly vulnerable.

### Just a chest infection

Sophie remembers that because David had so many chest infections, they felt like they knew the drill. She and her husband thought David might need some antibiotics but that he would be ok and get over it. They held off with the antibiotics and Sophie remembers that she slept in the same room as David and she noticed the rise and fall of his chest as he slept. With hindsight, Sophie thinks they should have just taken him to the out of hours GP but she thought it was better for him to rest.

The next morning, Sophie took David to the GP expecting to get an antibiotic prescription. The GP put an oxy meter on David’s finger and at that point Sophie still felt quite naïve. The GP listened to his chest and she said that he needs an assessment at A&E. Sophie remembers feeling that was probably just because it was the weekend so she was being extra cautious. Although David was a bit more chesty than usual, Sophie was still not too worried at this point.

### A&E rush

As they travelled to A&E Sophie remembers that her anxiety was definitely up a little bit. When they got to A&E Sophie remembers it was a rush and she could tell by the way the staff were behaving, that it was serious. They put an oxy meter on David and Sophie could see that his oxygen levels were at 72 or something, which was absolutely shocking. David was a robust and strong little character, but because he was so young, he deteriorated pretty quickly.

Sophie remembers that David was still smiling and trying to play at this point. Sophie is familiar with hospital as she used to work in one and her mum used to be a nurse. Therefore, the experience of being in A&E was more meaningful. She was aware they were in the resuscitation suite and that it was very serious. Sophie remembers eavesdropping on the doctors’ conversation and hearing a doctor say “not to just look at the child’s presentation because you’ll be fooled, look at his oxygen”.

### Thinking the worst

Sophie remembers that it spiralled really quickly. When the doctors said they needed to admit David and get him up to the ward, it was an awful moment. David was admitted to intensive care from the beginning.  Although Sophie didn’t vocalise it, she started thinking it was all her fault as she had been with him all night the night before. She thought that she should have taken him in sooner and not left it so late.

They still hadn’t given any sort of diagnosis at this point so Sophie was still thinking it could be a really bad chest infection or maybe something worse.

### The staff were phenomenal

Sophie remembers that the medical staff were absolutely phenomenal. They were so communicative in A&E, which she hadn’t expected in an emergency situation. Sophie can’t really remember how they handled it all, but she has no negative memories and therefore thinks it must have been handled well.

### Part of the team

From the moment they were in critical care, Sophie felt like a member of the team. They were so communicative at every step of the way and she was involved in decisions. Sophie wonders if the care was individualised and they had recognised that as an individual, it was really important to her that she knew all of the facts and could be involved in decision making.

Sophie cannot praise them enough and they helped her to feel safe and contained. The staff named her emotions when she couldn’t and provided reassurance. Sophie remembers a nurse in the middle of the night telling Sophie that David’s presentation was quite classic and although she couldn’t promise, she said that tomorrow they’d likely see a chance and he will start to improve. The nurse was right.

### Diagnosis

Sophie can’t remember exactly when they were given a diagnosis, as so much happened in a short period of time - David went from having a chest infection to pneumonia over a couple of days. It was relief to hear it wasn’t something really serious like meningitis.

### Being with David

Sophie stayed with David the entire week they were in hospital. Paul was in and out and it was straightforward for her to stay as there was no one at home to worry about at that point. Sophie remembers thinking that whatever David has to go through, as long as she was there to be his secure base and support him, then he wouldn’t be too scared.

Sophie and David had their own room which was fully equipped. Although she had her own bed, she hardly slept for three nights because there were staff coming in and out all of the time to check on David. David wasn’t sleeping through either and Sophie was too worried to sleep anyway.

### Dark moments

Two moments from being in hospital really stand out for Sophie. The first being the first night in hospital where she lay in bed thinking what “would I do if David died? How would I cope?”. Sophie questioned whether she would prefer to die, which is an unusual way of thinking for her as she has never thought like that before in her life. Sophie wasn’t sure whether she would be able to get through it or even if she wanted to. That was a dark moment for Sophie and she remembers being on her own with her thoughts as her husband was at home.

The other stand out moment was when the situation escalated quickly and the doctors said they might have to ventilate David. Luckily he got better about twenty minutes before they were going to ventilate him. Sophie was very grateful as she thought being ventilated would have been quite traumatic for David and some people don’t come back off a ventilator.

### Survival mode

Once they were home, Sophie was in survival mode for a few days as she had been in this fight/flight state at the hospital and it was suddenly over. Sophie and Paul still had to be cautious of David so she felt very anxious leaving hospital because she never wanted to go back there. Sophie remembers that she planned to do everything in her power to prevent something like that happening again because it was so horrendous.

### What caused the pneumonia?

When David was diagnosed with pneumonia, Sophie felt puzzled because she had always looked after him so well and kept him warm. Sophie's mum had previously commented on David's swallow but Sophie had dismissed it because she often picked up on things that turned out to be red herrings. However, following the time in ICU, Sophie thought there is no harm in checking it out.

### Shock and relief

The family paid for an assessment privately with a speech and language therapist who diagnosed David with dysphasia. Dysphasia without any other developmental disabilities is thought to be quite rare, but Sophie shared that is actually very under recognised and diagnosed. Sophie was shocked and relieved because it meant that the blame was taken away from her in some way - she hadn't done anything wrong, David just had this condition that no one knew about.

### Aftercare

After discharge and diagnosis, David continued to have respiratory care. He had regular check-ups with the aftercare team for about 6 months to a year which was always quite straightforward. David doesn't have asthma but he did have a viral induced wheeze for quite a while so they had an asthma pump inhaler.

### Over protective

Sophie recalled that the first winter after he was ill, she was anxious and a bit over protective in terms of keeping David and his chest warm. Sophie reflected that she didn't know any better the first time, but she had a responsibility to learn from her mistakes. She was very focused on prevention but mindful of not making David anxious and giving him a complex.

### Listening to professionals

The speech and language therapy team suggested that David didn't go to a big nursery as he is going to be prone to picking up bugs and coughs.
As a result, Sophie decided not go back to work for a while because she wanted to make sure that David was safe and well. Sophie did not want to put any of them back in hospital because it was so traumatic.

### Traumatic experience

Sophie would describe the experience as a trauma and she doesn't use the word trauma lightly. She didn't have any nightmares about it because David recovered and there was a good ending. Sophie reflects that for a while she was hyper-vigilant and fearful but this was not longstanding because he was ok. Even so, it was the worst thing that ever happened in her life.

### Save other families from the same experience

After David was diagnosed with dysphasia, Sophie ensured this was fed back to the respiratory team at the hospital. The consultant was amazing and apologised that they hadn't checked David, but it wasn't something they usually looked at. He reflected that it was a key part of his formulation and why he presented in the way he did. Sophie shared that as a result the hospital got some money to set up a dysphasia clinic for six months to assess children coming through.

As a parent, Sophie is glad that David's suffering meant that other children potentially could be picked up for dysphasia.

### David was so young

David didn't seem that phased by being in hospital or being unwell. Sophie remembers feeling grateful that he was so little and that she had been able to stay with him throughout as they both seemed like protective factors for him. Even though David had lines in and he did try to pull them out, there were not particularly distressing procedures. It was probably quiet unpleasant for him as he was grotty and poorly, but she doesn't think he ever felt frightened. The thing that David hated the most was not being to get out of his cot when he started to feel better.

### What David knows

David knows he was in hospital but Sophie is unsure whether he knows it was called pneumonia. He knows that he had a problem in his chest and he knows all about his difficulties with swallowing as he still has some thickener in his drinks.

### Talking about it as a family

Sophie and the family do talk about David's experiences so it is just normal for him. They don't talk about it as a problem, they called it his swallowing difference amidst talking about how everybody is different with different coloured eyes and hair. David is comfortable with it and sees it as something he was born with but something that is also changing.

As nothing particularly frightening happened for David and he was so young, Sophie thinks it is very much in the past for him and is not a conscious thing. It is part of his history and Sophie wanted to normalise that because he survived and he was strong throughout it all. The family are not preoccupied by it but they do talk about it sometimes, but not in too much detail. Sophie has told him stories about being in hospital, especially funny stories like the time he was sick all over her.

### Nursery was supportive

David was fine when he did start at nursery. He had the usual coughs and colds but his chest was more robust and Sophie had more confidence. David did attend a smaller nursery which felt a bit safer. Because the nursery was so small, Sophie remembers just talking to the staff about his condition and taking in his pre-thickened drinks. The staff were lovely and the manager was great which meant that Sophie felt confident they would do everything as she had instructed.

### Involving professionals

When David started at school, Sophie was worried that the significance of David’s dysphasia could get lost because on the face of it, it’s like a hidden disability. Sophie spoke with the speech and language therapy team at the local hospital who said it was quite normal for them to go into schools and do a bit of training with the staff. Sophie pushed for this a little bit as in her view, the school might not take it as seriously unless a clinician goes and speaks to them about it. So the speech and language therapist provided the school with a brief training session and a care plan. Sophie felt that this activated the system in a bit of a different way and the school made sure they were careful around certain foods and drinks. Sophie felt she had some good support.

### David now

Sophie described David as energetic, bright and a force to be reckoned with. He is sporty and academic and he can also be quite thoughtful and impulsive. David doesn’t have any other developmental delays but he does have ticks. The ticks come and go but Sophie first noticed them a year or two ago. She wasn’t sure and read a really good book about how tics are actually more frequent than we think they are. He definitely wouldn’t meet the criteria for a tic disorder but he has a propensity to tick for a few weeks and then nothing. Sophie reflected that her husband had ticks when he was younger too so there maybe something genetic. Physically, as far as Sophie is aware, David is healthy and strong and athletic which they are grateful for.

Sophie doesn’t think there is any kind of long term impact from the pneumonia. They just have to keep on top of the dysphasia, which is easier now he is older and can control his swallow consciously. It was harder when he was younger as he was all over the place and didn’t have that kind of control.

### David’s little sister, Amy

When David was just over two, his little sister Amy was born. Amy became unwell when she was around three weeks old with meningitis. Sophie didn’t know it was meningitis until she started to get better which she is grateful for. The lab results took a long time and she reflected that if she had known it was meningitis, she would have been terrified. Sophie was in disbelief when they told her as she was sure it was just a virus with a viral rash.

### Returning to hospital

Sophie found the experience of going to hospital a second time less scary because she had such faith in the staff. When she handed over Amy, she thought they’ll look after her. David was aware that his sister was in hospital but Sophie reflects that he wasn’t cognitively able and didn’t have a narrative around it. He didn’t know what it was like so Sophie and Paul normalised it so he just thought that is what happens when you have a baby sister.

### Impact on Sophie as a mother

Sophie feels that the experience had the biggest impact on her, in terms of her decision not to go back to work and return to her career, but also emotionally. For a while afterwards, there was a sense of guilt and Sophie constantly thought about what she could have differently?

### Family impacted too

The experience also had quite an impact on her parents, particularly her mum. The biggest factor which helped Sophie to put the experience in the past, and not require any additional support psychologically, was because there was not any sort of significant massive trauma. Although she worried about David dying, he never crashed so it never felt like ‘that was it’.

Sophie reflects that it definitely had a bigger impact on her compared to her husband. Paul was definitely more laissez-faire and as Sophie is the primary carer and takes more responsibility for the kids, she feels she was more anxious than him. Paul took it all in his stride and has the attitude that these things happen to children, it happened in the past and he’s fine now.

<u>No more children</u>

Although both of her children were fine afterwards, it has put Sophie off having more children. Although she has no belief that as a family they were being punished and that it was just bad luck, she just doesn’t want to risk it. Sophie doesn’t want to go through something like that again as it was just so exhausting and upsetting. She isn’t sure if they would have had any more children anyway bit was definitely ‘the nail in the coffin’ for that plan.

<u>Support network</u>

Sophie sought support from talking to her family and friends but she wasn’t offered any formal support. She may have taken it if support had been offered. Sophie remembers that she was definitely anxious, especially after David more than Amy as she learnt that children can be poorly and recover and be OK. After Amy, Sophie didn’t have the mental energy and ability to be anxious, she just wanted to carry on. She has a good friend who has a child with meningitis as well so she was very reassuring and helpful.

### *4.6.2 David's story*

**Figure 12**

*David's Timeline*

<u>His flap</u>

David thinks that why he had to go to hospital makes him unique. David is proud of being unique and having his flap. Although he thinks that his flap won't stay forever, he thinks it might even be gone, so he wondered if he should maybe choose something else to be proud of. David has a good understanding of what his mouth, throat and flap look like because he has a body book at home.

<u>David went to hospital as a baby</u>

David knows that when he was a baby, he had to go to hospital. He doesn't think this was that long after he was born. David knows he had to go to hospital because his flap goes slower. David thinks that when he was born, his flap showed.

David knows that before his mum and dad knew, they let him have swimming lessons and water came down his throat into his lungs, which is why he first had to go to hospital. After this, his parents knew he needed thickener, which thickens his drink.

### Memories of hospital

The first thing David thought he remembered about the hospital was when he was sitting in the waiting room and his dad came and gave him a snack. David thinks this might have been when he was there for his swallow.

Another main part that David remembers is that the doctors put something around either his toe or finger to measure something. David then remembered that it was to measure oxygen, he remembered that it was because his oxygen was 70. David remembers that when he was in hospital he was just lying in a hospital bed with the annoying thing on his finger. He doesn't think they gave him any meals, they might of, but he doesn't think they were that yummy at hospital.
David doesn't think he's been back to hospital since except for when his mum had to go for a check-up.

### Other significant moments

David knows that he was born at home and that there is a mark on the sheets where he was born that he can still see.

When David was 5, he went to 'Go Ape' and remembers going really high and he felt scared

### About me

David has a sister and a called cat called Binky. David is on the eco-council at school which means he has to clean up the school. David doesn't have a favourite colour he likes every colour. However his favourite colour used to be purple. David loves playing badminton and riding his bike. He also likes reading and listening to music, sometimes he likes drawing. David loves playing football and plays for a football team. He wishes he could trip the ball over his head and it went all the way into the goal.

### *4.6.3 David's story as told by Mary (Teacher)*

David at school

Mary shared that David is a lovely boy. He is enthusiastic and gets really into things at school. David is very confident and he isn't easily phased. He is very confident talking to adults. David is really likeable, thoughtful, and polite. David is really settled and well put together and gets on with things. Mary wouldn't have any idea that he has had any sort of medical trauma or anything like that. He is a very chilled and calm child.

Knowledge of his condition

Mary is aware that David had a condition that meant he couldn't drink water and he has to have his own drinks. He has thickening agent at school that he puts into water and Mary was told how to mix it up.. Mary didn't know why, she just knew he had a condition that mean he needed thickened drink.

David doesn't talk about it

David doesn't appear to be fussed by it and doesn't make a big deal out of it. He knows that he has a different drink and can explain how to do it. On the first day of school this year, they encouraged David to show them how to do it and he takes complete ownership of it. He doesn't need any help with it. Mary can't think of a time when David has spoken about going to hospital. Mary imagines if he it came up, he would probably be quite matter of fact. He is very bright and intelligent but he doesn't always necessarily put his hand up and contribute, so she can't imagine him giving up that information publicly. She doesn't think he would withhold it, but she hasn't spoken to him about it. Next term, they are learning about medicine and hospital in PHSE and Mary wonders whether he might offer up any more information about it.

## 4.7 The Identification of Common Themes and Differences across the Stories

To further explore the participant's experiences and answer the RQ, the narratives were analysed to identify commonalities and differences in their experiences of childhood illness. This section should be read in conjunction with the individual re-storied narratives of each participant above to answer the primary RQ. Once all of the stories had been read, transcribed and re-storied, the researcher drew on the aspects of the story and events which were emotive and meaningful for the participants to identify narrative themes. Each participant's story was colour coded into narrative themes and sub-themes. Appendix X, Y and Z illustrates how similar experiences and aspects of the story were identified across the three different groups of participants and then combined **(see appendix AA and AB**). The researcher engaged in an inductive data analysis to answer RQ1.

Some of the sub-themes highlight the experiences which were common amongst participants, whilst others are related to individual stories and contexts. Thus, the sub-themes demonstrate how CI was experienced and understood by different participants. Table 4 provides a summary of the 'narrative themes' and 'sub-themes' for the parents, teachers and children.

The rest of this chapter will provide a comprehensive description of the 'narrative themes and sub-themes' illustrating the similarities and differences across the stories. Extracts from the original interviews are given and the number in each bracket indicates the corresponding line numbers in the original transcripts.

## 4.8 Narrative themes and sub themes

The researcher recognises that the parent's stories of the child's CI were the richest and therefore the majority of the themes came from their narrative. This section is not to be considered in isolation, but should be read with the stories included above.

**Table 4**

*Participants' Narrative Themes and Sub-themes*

| Theme | Sub-themes |
|---|---|
| **The illness** | Parent intuition |
| | Admission to hospital |
| | Treatment was hideous |
| | Managing uncertainty |
| | Blame and guilt |
| **Coming to terms with the new reality** | Journey to acceptance |
| | Part of their life story and identity |
| | Grieving son |
| | Sense of perspective and gratitude |
| | Focus on the magical moments |
| | Sense of normality |
| | Other families |
| | Changes to family dynamic and roles |
| | Relationships |
| | Perfect storm for Christopher |
| | No more children |
| **Experiences of support** | Communication makes a difference |
| | Lack of professional support and guidance |
| | School support |
| **Impact of the illness on the child now** | Present and ongoing needs |
| | Nature vs nurture |
| | Child at school |
| | Age as a protective factor |
| | Strengths out of adversity |
| | Changing with age |
| | How it is communicated and understood |
| | Confusion and uncertainty |

| | |
|---|---|
| **Sharing information – communication and understanding** | Specific memories |
| | Teacher’s understanding |
| **The future** | Ongoing care and changes |
| | The future |

## 4.9 Narrative Theme: The illness

### *4.9.1 Sub-theme: Parents’ Intuition*

Their child’s diagnosis was a prominent theme for all parents as they spoke of the journey over time, starting at onset of illness. The onset of symptoms and subsequent admission to hospital was differing for each of the parents in the study, however they all described parental intuition that something was wrong: *“I just knew straight away that’s not right, a child doesn’t do that”* (Rachel, 144).

### *4.6.2 Sub-theme: Admission to Hospital*

The timeline and context of the admission to hospital impacted on how stressful this experience was for parents. Sophie and Alison had very traumatic and quick admissions to hospital, where they were admitted in an emergency*: “He was in intensive care from the beginning. Like what does that communicate to you? Like the maximum level of need… he was on oxygen*” (Sophie, 30).

### *4.6.3 Sub-theme: Treatment was hideous*

Although the initial diagnosis period was traumatic and stressful, Charlie, Adam and Ben required ongoing treatment and the parents narratives highlight that this was challenging. Laura and Rachel’s narratives portray a sense of relief once the tumours were removed and their child woke up: *“I had a banana in my hand and he reached out and grabbed it and I thought “I think you’re going to be alright” and it was a relief, a huge relief”* (Laura, 10). However, the unpleasantness of the chemotherapy quickly dominated this sense of relief, as parents described it as the worst part.

### *4.6.4 Sub-theme: Managing Uncertainty*

During the acute period of the illness, contemplating that their child might die was evident across all of the parents' narratives and caused emotional distress. Sophie described this period as dark moments: *"my child could die here and I'm not sure I'd be able to get through that, or even if I could get through it, would I want to?"* (33)

### *4.6.5 Sub-theme: Blame and Guilt*

Both Alison and Sophie experienced a sense of guilt and blamed themselves as mothers due to the way their children's conditions presented: *"he grew inside of me so it was everything was wrong I felt was my fault you know, did I do something? Did I eat something?"* (Alison, 67).

:*"there was a sense of guilt… what could I have done differently… cold I have picked up on things sooner*" (Sophie, 84).

## 4.7 Narrative Theme: Coming to Terms with the New Reality

As parents told their stories, it was evident that they had all been on an emotional journey that was not limited to the child's initial diagnosis and treatment. Parents described the ups and down of the journey as they came to terms with their child's illness. It was evident that the children's recovery was a source of anxiety for parents. Parents described feelings of stress, exhaustion, shame and depression because of their experiences. As Sophie reflected: "*because he recovered, there was a good ending so that there wasn't sort of that longstanding trauma...it was certainly up until that point...the worst thing that ever happened in my life...I would describe it as trauma*" (61).

Irrespective of the nature and severity of the illness, a prominent theme was the impact the illness had on their wider family. When children returned home, the challenges continued as families faced the practicalities of managing caring for their children. However, throughout the parents' narratives, despite the hardship and stress, the stories shed light on how the families managed.

### *4.7.1 Sub-theme: Journey to Acceptance*

This was particularly prominent in Alison's narrative as the journey to accepting that Adam has ongoing complex medical needs was a challenge:

> *I think I cried, the first year was tough, I wasn't sure if Adam would walk, I was petrified, I wasn't sure whether he would have the same milestones as other kids (119). I didn't change straight away, I still found it hard, I used to hide his ears.* (Alison (mother), 154)

### *4.7.2 Sub-theme: Part of their Life Story and Identity*

Parents recognised that they had tried to create a positive story around their child's illness as a way of helping the family come to terms with their experiences: *"it's part of his history and it's part of his story and I want to sort of normalise it because you know he survived it and he was strong throughout it all, and it's nothing to be ashamed of" (Sophie (mother) 84).*

Alison reflected that Adam has not known any different due to his medical conditions being present from birth. Although she believed this helped him to manage, she recognises that when they talk about having surgery in the future, Adam can get very upset. Alison described that if he meets a new adult he "*doesn't quite get that you just wanna talk*" (Alison, (mother), 83) *as* he is used to being checked at hospital. Adam's timeline highlights that being in hospital was not a significant event in his life story, this may be because he has spent significant periods of time in and out of hospital.  Alternatively, Adam may have also chosen to omit it completely as he did not wish to talk about it.

Charlie’s identity as a survivor was particularly prominent in his narrative and helped him to have a positive view of what he had been through*: “because I'm really proud that I survived it.” (235).*Charlie was keen to show the researcher his awards and trophies that he had for beating cancer (see Image 2) which act as a reminder that he survived.

### *4.7.3 Sub-theme: Grieving son*

This was a theme in Laura’s narrative as having two children with cancer at the same time and the subsequent death of Ben’s older brother, Josh, meant that her emotional experience as a parent was complicated: *“two months into that hellish experience my elder child was then diagnosed with cancer…which I just thought I don’t think I’m gonna manage this”* (Laura, 10).

Laura reflected that whilst thinking about Ben’s illness and recovery, it was hard to separate Ben from Josh. Although Ben has survived and is doing well, the family have had to manage the emotional turmoil of losing a child. Throughout Laura’s story, it is evident that although she is grateful that Ben has survived, celebrating this is complex.

### *4.7.4 Sub-theme: Sense of Perspective and Gratitude*

Throughout all of the parents’ stories, there was a sense of gratitude that their child was alive and doing well, which helped them through their journey. Throughout Rachel and Sophie’s story they used the word ‘lucky’ to describe their experiences. Whilst in Alison’s narrative, she drew on celebrating that Adam does everything that she would wish for. Laura and her husband wrote a blog about their experiences which helped them to build a positive view of a despairing time*: “it’s really amazing to be able to read it back cause sometimes you think what the hell happened because it was so insane*” (32).

### *4.7.5 Sub-theme: Focus on the Magical Moments*

This was particularly prominent in Laura's narrative as she described how looking back at their experiences and focusing on the special moments helped her to manage:

> *It was the best of times and the worst of times… I mean the magical moments we had, the amount of time we spent with our boys that you wouldn't have gotten… and the intensity and level of connection and relationship we have with Ben* (Laura (mother), 43).
>
> *They walked out of that hospital holding hands together and I think you know, with whatever happened next for Josh, that was just a really amazing sight to see really that Ben had the support of his brother all the way through* (Laura (mother), 10).

### *4.7.6 Sub-theme: Sense of Normality*

Creating a sense of normality was important to help families manage the uncertainty of the situation: "*Charlie was never really ill because of the chemotherapy and he could do things like playing and going on activities, so that was our priority as a family I think it was just kind of trying to get through"* (Rachel (mother), 55).

Whilst, in the children's narratives, the illness, although a significant event, was framed as one of many events that happened in their lives: *"I think I just stayed in hospital for a bit more and then… and then we went to Cadbury land"* (Charlie, 206).

Alison acknowledged that for her, it will never be normal, however she found comfort in normality: ""*it's a normal household…I do exactly what I did with my first daughter"* (Alison (mother), 67).

Whilst for Laura returning to normality was not a positive experience because everything had changed:

> *I always say… when you get a diagnosis you… step out of the ordinary and you step into the extraordinary and you lived this extraordinary life… and then one day that will stop and you have to pretend to be normal again.. you don't ever feel normal again, you just feel like you're wearing a mask*. (Laura, 45).

### *4.7.7 Sub-theme: Other Families*

For both Alison and Rachel it was important to be around other families going through a similar experiences as a source of support and comfort: *"it wasn't explicitly necessarily talking about it, but it was just being with people who are going through similar journeys*" (Rachel,112).

*: "in the beginning it helped but I just don't think that I need it anymore because Adam now sees other deaf children in school"* (Alison,109).

Whereas for Sophie being able to help other families was a source of comfort. Following David's diagnosis of dysphasia, Sophie's feedback to the hospital meant they opened a dysphasia clinic: *"it's just really under diagnosed and under recognized, so it was really, it felt good that actually, David's suffering meant that other children potentially could be picked up."* (Sophie,57).

### *4.7.8 Sub-theme: Changes to Family Dynamic and Roles*

Parents' priorities changed throughout their journey as they adapted to what happened. For Rachel, whenever Charlie spent in hospital it felt like they were wasting time that could be spent together, particularly when the family didn't know the prognosis. However even when home, Rachel recognised that her priorities were still different as a family: *"So I think it was just survival mode for* *about two to three years of just the practicalities of getting to treatment and blood counts"* (Rachel,53).

Whilst Sophie was adamant that because David had recovered from his acute episode of pneumonia, she was determined never to let it happen again*: "I'm gonna do everything in my power to prevent something like that happening again… I felt this responsibility… it's important to learn from your mistakes, prevention, I was quite focused on prevention"* (Sophie, 86).

Throughout the stories the change to the family routine and dynamic was a prominent theme as parents had to manage the logistics of caring for their children. All parents' stories made reference to the impact it had on their career choices, as parents had to give up their jobs and change their working patterns due to spending large amounts of time in and out of hospital and wanting to keep their children safe.

Parents' stories illustrated how important it was to have a support network of family and friends around them during this period to mediate the changes:

> *I don't think I knew what was in our fridge for two years…and that was amazing there was always something on our doorstep and just some friends who were willing to just turn up at the drop of a hat to help you with the next new difficult thing you have to deal with that cancer throws at you.* (Laura (mother), 34).

Parents recognised that their role changed throughout their child's illness. Parents described advocating for their child's care and it was important to be informed so they could advocate appropriately. Alison described wanting to know everything about her sons condition so she could be prepared for anything that happened. Whilst Rachel reflected that researching Charlie's brain tumour not only helped her to handle the uncertainty, but also so he could ensure he got the appropriate care. For Laura, her role as an advocate, started before Ben was even diagnosed:

> *I took Ben to the GP that day and he said oh he looks happy enough to me... and I physically could not get out of the chair and I can't go home cause I don't know what to do so you're gonna have to do something* (Laura (mother), 4).

### *4.7.9 Sub-theme: Relationships*

Parents recognised that their relationships have strengthened following the CI, although it has been stressful: *"our relationship definitely suffered during it and I think we're now just about coming out stronger the other side of it"* (Rachel, 195).

Whilst Alison reflected that : *"Adam sleeps with me, my husband sleeps on the sofa and you can imagine that causes a bit of a problem in the relationship at times, but it is what it is".* (83)

Sophie and Alison acknowledge that the experience impacted on them more than their partners as they were the primary caregivers who were in hospital with their children throughout. Although the parents' stories also highlight how so many people can be affected by childhood illness, including extended family and the professionals involved in the care.

### *4.7.10 Sub-theme: Perfect Storm for Christopher*

Throughout Rachel's story, the impact that Charlie's illness had on his older brother was a prominent theme. Christopher continues to present with anxiety, which Rachel attributes to the fact he understood how worrying it was and *"entered the word of illness more than Charlie did"* (42). Rachel recognised that Christopher: *"lost so much control over his life when his brother was unwell and in hospital, he missed his birthday party, his whole life was affected"* (Rachel (mother), 201).

### *4.7.11 Sub-theme: No More Children*

Two of the parents described that due to the distress of their children's illness, they wouldn't have any more children *: "I've got a family and I'm lucky to have that but yeah it scared me, I think the thought of going through this again petrifies me"* (Alison, 134). Whilst Sophie shared that: *"We may not be as fortunate the third time, something awful might happen…let's not run the risk"* (133).

## 4.8 Narrative-theme: Experiences of Support

The level of support that families received varied across the stories. It appeared that the more severe the child's ongoing medical needs were, more contact and *check-ups* with medical professionals occurre*d.*

### *4.8.1 Sub-theme: Communication makes a Difference*

Parents recognised that professionals held a lot of power in terms of their child's care. Parents appreciated clear communication from professionals during their child's illness and this helped them to manage the uncertainty. It was important that parents felt listened to and were part of the team as this provided emotional support whilst in hospital: *"they were just so communicative every step of the way. Everything that was happening, we were involved in the decisions, they were just amazing…that made me feel so safe and contained*" (Sophie (mother), 30). Sophie's positive experiences in hospital meant that when her younger daughter had to spend time in hospital it was less scary as she had faith in the medical team.

Despite initially blaming the NHS for not noticing Adam's heart condition, Alison has felt well supported since. Alison values her relationship with his urology team as they know Adam and are available whenever she needs something, which helps her feel contained.

#### *4.8.2 Sub-theme: Lack of Support and Guidance*

A lack of support was prominent throughout Rachel's story as she navigated the unknown, particularly in regard to making decisions about ongoing care. When Charlie transitioned to oncology the family lost confidence in the team as communication was poor. Additionally, administering chemotherapy at home was particularly challenging: *"there was nobody because you were an outpatient by that point there was nobody that was there to support you in helping your child to do that and that was horrible*" (Rachel (mother), 131).

Rachel acknowledged that charity services were a life line for the family:

> *If it wasn't for them, then it would have been even worse…When the hospital weren't sending blood tests and things, I could just send the nurse a text message and she would be able to relay the messages and sort it out* (Rachel (mother),181).

The logistical support meant that the family could continue with their routine and mediated some of the challenges that came with having a critically ill child. Rachel and Sophie reflected that they were not offered any sort of psychological support in relation to their child's illness: *"it's almost like, well he's had it just be grateful which we are so grateful, but you always then feel bad for asking for anything to help kind of process it all" (*Rachel (mother) 96).

Whereas Laura recognises that support may have been available, but due to the family context she: "f*ound a lot of professionals being involved quite invasive cause our lives were so out there"* (Laura (mother), 30).

Rachel acknowledged that it would have been helpful to provide some direct support for Charlie to acknowledge what he has been through but also for his brother: "*they're kind of on the journey aren't they and they're the ones that get left behind sometimes"* (Rachel (mother), 49).

### *4.8.3 Sub-theme: School Support*

Across the stories, having a supportive school environment was identified as a protective factor for the child, particularly when staff were willing to listen to parents concerns and requests.  Alison was worried when Adam started school, but he settled instantly. As Adam has hearing loss, it was important he went to a school that provided specialist support, Alison reflects that she has found the best school for Adam because he is around many other children with disabilities.

It was important to parents that the school were aware of what had happened*: "he does mention it when it's relevant.., the teachers can support him with that and have conversations with him"* (Rachel (mother), 189).

Similarly Laura has found the school very supportive as they acknowledge the severity of Ben's experiences:

> *Sometimes Ben will get sort of very scared of an image that might come up that would be innocuous  to anyone else and I think there's a bit of his trauma suddenly comes out and they're very open to me saying - how can we deal with that? They don't brush it off and they take these conversations seriously (*Laura (mother), 130).

Teachers also acknowledged the importance of having a supportive relationship with the family, as they described having open and honest communication where they could chat about anything. In Ben's case, Mark (teacher) recognised that most of the support is to do with his brother's death as opposed to the fact he had a brain tumour himself. Mark shared that there is a 'Josh' day, which Ben takes part in every year.

## 4.9 Narrative Theme: Impact of the Illness on the Child Now

Parents' narratives focused on the experiences of the child over time, throughout their illness and into recovery.

### *4.9.1 Sub-theme: Present and Ongoing Needs*

Both Laura and Rachel described the challenges of recovery as their children present with ongoing issues with eating and sleeping which are attributed to their past treatments. Sleep was identified as a common issue across three of the parents' stories: *"whether something in the surgery just knocked something you know, like whatever it is that makes you go to sleep… basically so even if he's exhausted he just will not switch off and go to sleep" (*Rachel, 136).

The extent to which the children continue to present with emotional sequelae was attributed in part to how traumatic and serious their experiences were, as Sophie reflected: *"because there was no kind of point at which something really frightening happened, I think it's very much in the past for him, and it's not conscious either"* (Sophie, 84)

Although Ben is doing well now, Laura describes that he can still go from: "*zero to 100"* (Laura (mother), 54) in terms of his emotional regulation, which she attributes to his past experiences. Whilst at school, Mark described that Ben presents as very well regulated: *"considering what he's been through, he's really stable. I'm quite impressed with the way he copes with things"* (Mark (teacher), 12).

Both Ben and Charlie have an aversion to medication. Laura described how this impacts on Ben's day to day as is related to his brother passing away: *"he's very fearful of people being ill and their medicine working… I think it's quite mixed up and I think one thing that is really hard for him to understand is why his medicine worked and Josh's didn't"* (Laura (mother), 62).

Alison's narrative illustrated her past worries that Adam would not walk or function as a result of his condition, although he has surpassed all expectations. Adam to have physical care needs including his colostomy bag, wearing a BAHA hearing aid and issues with eating, however neither Allison or his teacher consider these barriers. Alison described that Adam has some learnings needs which his teacher attributed to his missed experiences: *"the staff at school explained to me… when normal babies crawl...they're already learning, you know Adam was in hospital most of his early stages of his life in and out"* (Alison (mother), 83).

### *4.9.2 Sub-theme: Nature vs Nurture*

Across the stories, it was evident that the adults were unsure whether their experienced had any impact on the children's personalities*: "what would he have been like anyway… who knows nature vs nurture"* (Laura (mother),103).

Similarly, both Sarah and Mark acknowledge that it can be hard to know if their brain tumours have had any impact on the boys at school: *" he has a problems with concentration, basically, which could be just 'cause of his age or could be because obviously what he's been through"* (Mark (teacher), 2).

### *4.9.3 Sub-theme: Child at School*

Some of the parents' narratives illustrated that's starting school was coupled with a sense of anxiety and anticipation that the child would find it difficult. However, across the stories it was evident parents experienced a sense of relief that their children are doing well. Laura acknowledged that When Ben first started school it was hard to know if anything was going in as he was so quiet and serious. Laura recognises the covid-19 pandemic allowed Ben to spend more time at home, which she believes helped him *come: "more back to life"* (Laura (mother), 82).

All four of the children were described as very sociable and popular by their teachers and they reflected that the children do not stand out compared to their peers, which can make it easy to forget what they have been through: *"to someone coming from the outside, you wouldn't have a clue"* (Mark (teacher), 28).

: *"[Charlie's] just so happy go lucky at school and doesn't cause us any problem. He behaves beautifully, makes the right choices. He's a really good role model."* (Sarah (teacher), 33).

Tracy acknowledged that apart from Adam's physical differences and physical care needs *"he presents as a typically developed child*" (teacher, 19).

### *4.9.4 Sub-theme: Age as a Protective Factor*

Across the stories, age was identified as a protective factor in terms of how the child experienced being in hospital but also their recovery: *"he didn't seem that phased by it at all, I remember feeling quite grateful that he was so little and that I'd been able to stay with him throughout, both of those factors were sort of protective factors"* (Sophie (parent), 63).

*:"because of his age, and how elastic the brain is there's much higher chance that he would be able to get movement back"* (Rachel (parent), 156).

### *4.9.5 Sub-theme: Strengths out of Adversity*

Some of the parents described strengths that their children have developed as a result of their experiencing of CI. Both Laura and Rachel acknowledged that their children were able to occupy themselves well, which they attributed to their experiences of being in hospital and not being active. Both Alison and Rachel describe how their children are strong and able to overcome challenges: *"he's strong he's really tough and he's overcome more in his little life than most people go through in their whole life"* (Alison (parent), 33).

*:if he's like nervous about something or not so keen on something, he'll he always physically get a grip of himself and he's like determined to do it... kind of think is that just because he's gone through things where you know he's got to do it* (Rachel (parent) 67*).*

### 4.10 Narrative Theme: Sharing Information – Communication and Understanding

#### *4.10.1 Sub-theme: Changing with Age*

Across all of the stories it was evident that as the child was young at the time of their illness, their understanding was changing with age as they developed the language and cognitive ability to process what had happened to them. Parents acknowledge the importance of talking to their child about what happened yet following their child's lead: *"he is obviously questioning it more as he gets older and you want to make sure you support him in the right way and I don't want to get him really worried"* (Rachel (parent), 191).

*: "as Adam's growing he asks me questions, "why are my ears small mummy? Why have I got this mark here mummy?"* (Alison, parent, 31).

Both Laura and Alison acknowledged that the time will come for their children to understand their past experiences as they continue to develop an understanding of what happened.

#### *4.10.2 Sub-theme: How it is Communicated and Understood*

Parents recognised that they used a range of approaches to support their child's understanding. Alison and Laura described using pictures to help their children to understand what happened:

> *there are some crazy pictures of them running around with some bandages on their heads and no clothes on and their central lines hanging*

> *out, and it's quite an usual photo and he's like fascinated by that… like "what was on my body?"* (Laura (parent), 62).

All parents recognised the importance of using child friendly and simple factual language to explore their experiences:

> *He wouldn't have understood words like chemotherapy… we said basically the doctors taken the tumour out which is amazing… so you've got to take this medicine which is horrible but we just explained it as you know, it is to try and make sure it doesn't grow back.* (Rachel (parent), 78).

Whilst, Alison's narrative focused on how she talks to Adam, as she told him that the doctors had to fix the hole in his heart using sellotape as this was an analogy she felt he would understand. Alison has used positive child friendly language with Adam as he describes his BAHA hearing aid as his 'magic ears'.

The way parents had explained the illnesses was evident in the children's stories as both Charlie and David spoke about their illness in reference to the facts of what had happened to them. For example David drew a diagram on his timeline (see Figure 12) and his narrative around this highlights that he attributed his illness to his flap being slow. Both children also had some knowledge of how their parents had come to realise they were unwell, which was based on their parent's stories about their experiences. Adam demonstrated a less coherent understanding, however as identified, Adam has some language difficulties. An exploration of his experiences of hospital was explored using the Playmobil set (see Figure 5). Adam shared that he knows he has been to the doctor to check his hearing:

*"LS: what did you do at the doctor?*
*Adam: they check my hearing **touches headband***
*LS: is that what this is on your head?*
*Adam: so I can hear" (62-65).*

### *4.10.3 Sub-theme: Confusion and Uncertainty*

Despite clear communication from parents, confusion and uncertainty was a recurrent theme in the children's stories. Although both Charlie and David expressed an awareness of what happened to their bodies, it was evident that there are still aspects of their experiences that are unknown and they are still continuing to develop their understanding of what happened. Charlie has a clear understanding of the physical impact of his illness, there is still some confusion about the causation behind these experiences. Charlie believes that his hair fell out: "*because my brain tumour was affecting my head so it just fell off"* (331) and whilst talking about the chemotherapy medicine; Charlie wondered: "*was it a type of poison?*" (348).

Parents shared that they are unsure how much their children remember or understand. Laura described how Ben will:

> *Pretend to remember it, or he goes back to something I don't know what… it's hard to know cause it comes out in bits and bobs and at very unusual times we will suddenly get a question about something…we were just playing and then he said "how did they get this thing out of my head?"* (Laura, 58).

In contrast to other parents' narratives where the focus was on their child as a survivor, Laura's story highlights the complexity of their situation as Ben's understanding of his experiences and journey with cancer are confusing due to his shared experiences with his older brother Josh. Laura reflected that it has not been appropriate to continuously talk about the past, acknowledged that if Josh had not died, they may talk about it more. Mark also acknowledged that Ben doesn't talk about his brain tumour, although: *"he'll mention Josh and he'll draw Josh and he'll talk about Josh as if he's still about"* (Mark (teacher), 12).

Laura described how Ben has developed his own way of communicating how he feels through drawing and will share how he's feeling, how he makes sense of the world and how he feels safe when he is not with his family.

### *4.10.4 Sub-theme: Children Understanding: Specific Memories*

The children's narratives included memories of specific equipment, places and people that stood out to them as significant. Charlie talks about how visiting the hospital helps him to remember more about it, whilst David remembers the equipment in the hospital: "*I remember…when they put this thing around my toe or maybe around my finger and they were measuring something"* (David (child), 29).

Whilst Adam, when exploring the play Mobil equipment, he spent a long time inspecting the 'splint' and stethoscope which may have been familiar to him.

Whilst talking about learning to walk again Charlie smiled:

> *I had to learn how to walk and my brother would jump in about and then I actually walked… because I wanted to jump about so my brother was kind of the reason why I walked and then I walked to my dad* (Charlie (child) , 209).

### *4.10.5 Sub-theme: Teacher's Understanding*

The extent of the teachers' knowledge about the illness varied across the four cases, influenced by what parents had shared, how much the child talked about it and whether there were ongoing care needs. Some teachers knew the child's medical history and the challenging journey that the family had been through. This was the case for both Ben and Charlie who had older brothers at their schools when they became unwell, which meant that staff were already aware before they started. However, no specific prep was put in place "*because when he started [Ben] was on the road to recovery"*. (Mark, 24). Information about most of the children was shared across the school between staff, mostly so they could be alert and considerate towards the child and their family if needed:

> *I think obviously everyone was made aware of his situation and too um obviously, not necessarily treat him different, but be aware that there might be, he could well struggle with certain areas, especially like things like memory and stuff like that.* (Mark (teacher), 24).

Sarah is also aware of what Charlie has been through because he talks about it a lot:

> *he's fabulous at talking about what he's been through…he articulates what he's been through and he's is so happy to talk in front of the rest of the class if it ever comes up, or if anything is related…just entered into that conversation with I went through that Mrs but I was lucky enough to survive"* (Sarah (teacher) 2).

David's current teacher's knowledge is only related to his ongoing care needs, which had been passed on from his previous teacher. She was not aware of medical history, and doesn't believe that David talks about it:

> *So that's all I know, I didn't know why, I just knew that he had a condition that meant he had to have thickened drink, that's all…he's not fussed by it, but doesn't make a big deal out of it, like, just said yeah this is my drinks I have* (Mary (teacher), 6-8).

Tracy is the only teacher who has had communication with medical professionals, partly due to Adam's ongoing care needs. She met with the urology nurse, and felt that she was well supported as she was trained and before Adam started at school. Tracy acknowledged that Adam does not currently talk about his past, however, staff encourage him to explore his identity through play as they aware of what happened:

> *I think he's still processing a lot of that and actually doesn't have the language to process that in the way that another child his age would so you know we've done a lot with dolls with colostomies and dolls with headbands and things* (Tracy (teacher), 41).

## 4.11 Narrative Theme: Looking to the Future

This was a common narrative theme which illustrated that even when a child is doing well, recovering from the period of illness is a daunting journey. Whilst reflecting on their journeys, it was evident parents recognised the future is uncertain: "*I definitely don't want for him to ever say "Oh I can't do that because I had a brain tumour"…or freak out about how ill he was and start really like worrying about it coming back"* (Rachel (mother), 86-90).

Similar considerations were made by teachers, who recognised that the children were still young: *"hopefully this isn't something that will come back later on and really hit him when he's sort of like understands it a bit more when he gets a little older"* (Mark (teacher), 36).

### *4.11.1 Sub-theme: Ongoing Care and Changes*

All of the children have ongoing medical check-ups or health needs to differing degrees. Rachel feels that Charlie is beginning to develop a more coherent understanding of what I means to have had a brain tumour as after his most recent scan, he seemed relieved for the first time. Charlie's story focused on his ongoing check-ups: "*when I was in hospital I have to take these needles which I really didn't like…but when they took them off, it really hurt…so I do the scans instead of the needle*" (Charlie (child), 251-255).

Alison's story, although positive, also highlighted that she will worry every day for the rest of her life. Throughout her story she acknowledged that she worries about Adam's future, whether he will be bullied due to his physical differences and whether he will have children; something she doesn't think she should worry about as he is only four. Alison is hopeful that Adam will be able to have corrective surgery whilst he is still young, so he learns to adapt. Adam demonstrated an awareness that he is going to have an operation in the future as he shared that he is going to have surgery to get a new head band soon. Within Tracy's story, she acknowledged that Adam seems to find the uncertainty about upcoming surgeries difficult, particularly due to last minute cancellations because of Covid-19: *“somethings going on there, I think the uncertainty…because now when Alison says to him we're going in for your surgery, he probably thinks “are we though?””* (Tracy (teacher), 43).

### *4.11.2 Sub-theme: The Future*

Across all three of the children’s narratives, one of the most defining and dominant themes was their life now and the focus on the present and future. The children constructed themselves as individuals defined by the activities they take part in and the interests they have in their everyday lives. All of the children spoke about their interests and things they enjoy doing. Both Adam and Charlie drew a self-portrait which included their parents highlighting how important their relationships are. Adam’s important events on his timeline-included time spent with his dad at home, whilst for Charlie, described that he smiles when he is family are happy.

## 4.12 Summary of findings

The storied narratives illustrate how uniquely childhood illness is experienced by the child and their parents’ over time. In addition, teachers’ storied narratives illustrate how childhood illness is understood and perceived in the school context. Through the identification of the similarities and differences across the stories, it has also been possible to further address the RQ. In summary, the key findings include:

- The CI journey, from onset of illness to now, included many ‘ups and downs’ as perceived by the parents
- The CI impacted on the entire family and affected relationships, roles and dynamics
- Support from professionals, friends and family made a difference to the families’ experiences
- Parents’ hold the story about their children’s CI and choose to share this with school

- Children look towards their parents for clarity and information about their experiences of CI
- Children's understanding of their CI changes with age
- Parents continue to try and accept and move on from their experiences as they look towards the future

The research findings will now be explored in Chapter 5. The researcher will explore the individual storied narratives and shared narrative themes in relation to the RQ, the research discussed in Chapter 2 and relevant psychological theory.

# Chapter 5: Discussion

## 5.1 Introduction

This chapter will present a discussion of the findings and insights from this study. The main findings will be outlined and discussed in light of previous research and theory. This will be followed by a critique and consideration of the trustworthiness of the study. To conclude this chapter, suggestions for future research and implications for practice will be presented.

## 5.2 Aim of the research

The current research was exploratory by nature, with the intention of gaining an in-depth understanding of how CI in early childhood is experienced and understood by children, their parents and school professionals. The following section will explore the insights gained through the stories, in regards to previous literature and relevant psychological theory. The intention was to answer the central RQ:

*"What are the stories told by young children, their parents, and their teachers about their early childhood illness?"*

This section will discuss the narrative themes which were salient to the participants' experiences, allowing for comparison across the differing stories and contexts.

## 5.3 RQ: What are the Stories told by Young Children, their Parents, and their Teachers about their Early Childhood Illness?

Within the current study, parents' narratives hold the richest information and can be considered the dominant stories. Parents' were able to offer insight into how CI was experienced by the family, as they were present for the duration and had more understanding of what was happening than the children themselves.

Parents' stories consisted of connected events that illustrated their experiences of realising their child was unwell, navigating the systems around their child's illness and treatment, and the journey towards acceptance and recovery over time. Participants' stories were idiosyncratic by nature as although there were some shared storylines, these were experienced differently by each parent. The children's and teachers' stories about the illness were shaped by the parents and it is important to consider this when drawing comparison across the three groups. The parents' stories about their children not only shape their own understanding, but also the way the children understand their experiences and also the way that teachers view the child. Comparison across the stories will be made in relation to the overarching narrative themes.

## 5.4 The illness

The experience of admission to hospital, diagnosis and treatment was a significant plot in parents' storylines which illustrate how childhood illness can be conceptualised as a journey, not as an isolated event. In the current study, it was evidently important for parents to return to the beginning to provide context to their experiences over time. Similar findings were evident in the literature (Atkins et al., 2012) who recognised that parents need to talk about their experiences of diagnosis and the admission to hospital to make sense of them.

The current findings recognise that parents were primarily concerned with their child's survival, describing this acute phase as particularly difficulty as they had to manage the uncertainty about their child's prognosis. The significance of the early events in their stories was related to their emotional reaction. For some, it was a sense of relief to get a diagnosis as it confirmed their intuition that something was wrong, and meant that 'the doctors' would intervene to handle it. Whilst for others, a diagnosis came with a sense of guilt as they felt that they could have done more to prevent it. The most significant aspect of the child's admission to hospital, prominent in the stories and the major stress, was a realisation that their child might die. Children's time in hospital and ongoing treatment varied across the stories, which also impacted on how salient these early experiences were and the disruption they caused in the family.

Once they knew their child was going to survive, parents were able to shift their focus to how they would navigate and adjust to the changes. Similar findings were evident across the literature (Fayed et al., 2020; Foster et al., 2019; Jones et al., 2021; Wray et al., 2018). This also supports the ‘biopsychosocial model’ proposed by Atkins et al. (2012). The authors recognised that parents are often in a state of just coping initially, without really processing what was happening, which was similar to how the current parents told stories about those early stages of the illness.

The researcher recognised that all of the parents’ stories held an optimistic tone which could be in part due to the therapeutic value in retelling their story as storytelling can be a way to re-store order following disruption (Becker, 1997). This was likely the first time parents told their story in its entirety for many years and they drew on what they found important and significant. Additionally, it has been some years since the children were first admitted to hospital and the trauma of that time may have diminished as parents adopted a new perspective. This was also evident in Atkins et al.’s (2020) study where parents were able to look back on what happened with a different outlook. As one parent recognised, because her child has survived and overcome so much, she no longer feels traumatised by the experience, which at the time was incredibly upsetting. In the context of CI, the stories illustrate that the psychosocial demands of this situation evolved over time, depending on the condition, context and long term prognosis.

## 5.5 Impact on the Child Now

Parents’ stories about the children focused on how they were initially affected by the illness and how this had changed over time. The direct impact of the illness was mostly associated with residual physical concerns, for example issues with sleeping and eating. When the child’s medical condition is still prevalent, it was prominent in the parent’s storyline as they explained not only what these conditions were, but what it meant for their child. This was the case for Alison, who continues to navigate the uncertainty about her child's physical health.

As parents told their stories, it was evident that they were less assured as to whether there were psychological and emotional implications of the illness for their children. However, where there was emotional adversity, parents reflected that how traumatic the child had found their experiences may have had an effect. Parents' recognised this may be attributed to their age, duration and context of their illness. For example, David's CI was so acute that Sophie feels he was not affected at all by his experiences. Whilst Laura recognises that Ben does present with some emotional regulation difficulties which she attributes to the emotional distress he experienced during chemotherapy treatment. Parents in this study seemed to take comfort in the fact their children did not particularly remember their experiences as they recognised that their age meant they were easily protected from the stress of the situation. In contrast to what is reported in some of the literature, most parents not feel their children were particularly traumatised by their experiences of illness. This may be explained by research which recognises that how stressful an experience is, is related to one's subjective interpretation of that experience (Dow et al., 2012; Kazak et al., 2006).

As recognised in the literature, there is a focus on measuring outcomes as a result of illness across cognitive, health, psychological and social domains (Fayed et al., 2020). This focus on outcomes within the medical field may have impacted on how parents viewed their children. Within the stories, parents made reference to the information they had accessed about the possible negative outcomes associated with their child's illness. However it seemed that throughout their stories, parents reflected on their child's progress in comparison to this information, which allowed them to look back with a positive perspective.

All of the studies discussed in Chapter 2, reported that children experienced a range of psychological and physical sequelae due to their experiences of illness. Although some ongoing negative implications were recognised in the current study, the severity and longevity of the symptoms was not a significant aspect of the stories. Within the literature, it was recognised that the emotional adversity experienced by participants, was closely related to the child’s physical recovery and functionality (Foster et al., 2019; 2020; Jones et al., 2021). It was apparent that parents in the current study did not perceive their child’s illness as a barrier to their engagement with life, outlining that now their child was able to do everything any other child could.

Similarly the way that teachers talked about the children was filled with positive language, focused on how well adjusted and successful they were at school. Yet teachers’ also drew on comparisons with their preconceived ideas of children who had experienced CI, as they recognised that they would have never known what the child had been through if their parents had not shared. These findings are in contrast to the two papers in the review which focused specifically on the child’s re-adjustment to school as they recognised that it can be a challenge as a result of ongoing adversities (Jones et al., 2022; McKevitt et al., 2018). However, both Alison and Tracy’s stories reflect that Adam does present with some cognitive and language issues which his teacher attributes to missed incidental learning and issues with hearing. Nonetheless, this has not made his adjustment to school any more difficult due to appropriate support being in place. This is similar to the findings in the literature, as the more evident and severe a child’s needs were, the more consistent and organised the support was.

## 5.6 Coming to Terms with the New Reality and Experiences of Support

### *5.6.1 Wider Impact*

The literature discussed in Chapter 2, recognises that CI can impact and effect the dynamics and relationships within the wider family (Atkins et al., 2012; 2020; Jones et al., 2021; McKevitt et al., 2018; Williams et al. 2018). CI puts strains on family life as it places demands on family resources, including influencing parents work patterns (jones et al., 2021; Lerrett et al, 2017). The parents’ storied narratives illustrate how CI was considered a disruption as it dominated and overwhelmed many aspects of their lives. The family context influenced how the illness impacted on individual members. For example, within her story, Rachel recognised the negative impact the CI had on Charlie's sibling. This was a significant theme in her story reiterating that a child's illness does not occur in isolation and has implications for the wider family. As Rachel reflected on their experiences, she recognised there was a lack of understanding and consideration that Christopher, although not unwell himself, would be affected by the experiences, suggesting there is a lack of support which recognises the impact on families as a unit.

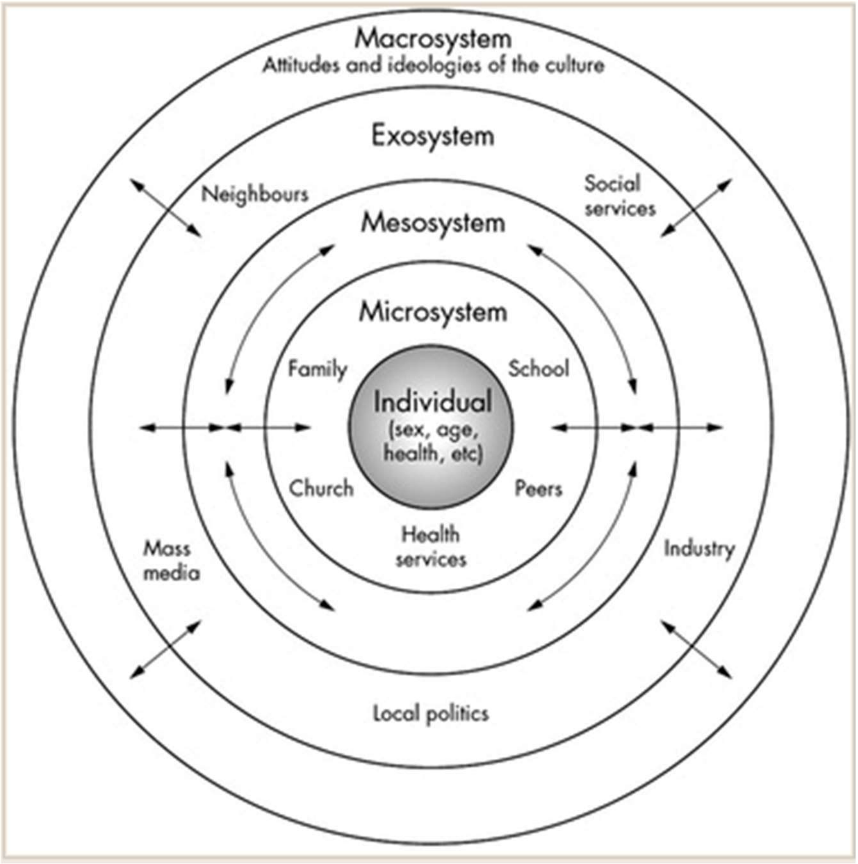
### *5.6.2 Coming to Terms and Coping*

As a result of the disruption to family life, there was a strong desire for parents to create a sense of normality to provide some consistency. Similar findings were found across the literature as parents desire to return home provided a sense of control (Foster et al., 2019). The idea of a 'new normal' (Atkins et al., 2012; 2020) was prominent in the narratives as parents recognised life had changed. In the majority of stories, the CI appeared to provide an opportunity for parents to evaluate their lives and what was important. Parents no longer worried about the 'small things' and were grateful for their strong familial connections. The current study did not focus solely on the negative implications of childhood illness, instead the findings highlight the range of positives that came from these experience, congruent with evidence that people can experience PTG following adversity (Tedeschi & Calhoun, 2004).

Parents' narratives were optimistic despite the adversities they had faced. The way that parents' narratives demonstrate resilience is of interest and can be considered in light of the FRF (Walsh, 2006). An important aspect of FRF, is considering the unique individual context of each family. Walsh (2021) postulates that there are three key processes which are central to how a family experiences and manages adversity; facilitative beliefs, organisational resources and communication processes. Walsh (2021) recognised that resilience is not a static concept and is dynamic as a result of ever changing interactions across systems. She postulates that in light of Bronfenbrenner's framework (1979): "the family, peer group, community resources, school or work settings, and other social systems can be seen as nested contexts for nurturing and reinforcing resilience" (p. 257).

**Figure 9**

*Bronfenbrenner's Ecological Systems Framework*



### *5.6.3 Bronfenbrenner's Framework: The Micro-System and Family*

At the family level, Walsh (2021) recognises that each individual family will hold beliefs about the world around them which will impact on how they handle adversity and make meaning of their experiences. Across the narratives it was evidently important for parents' to share their story about their child, to acknowledge what had happened and reflect on how distressing it was. Through reflecting on these experiences, it appeared that parents had been able to accept and contextualise their emotions as appropriate at the time. Throughout their journeys, parents had to handle large periods of uncertainty. It was evident that parents' capacity to manage this uncertainty was a result of both being informed as best they can, whilst also accepting that they will not always have the answers and there are some things they cannot change. Through accepting this uncertainty, they were able to move forward.

Parents drew on how important their family relationships were during the peak of adversity and also in their recovery journey as being together was the priority, despite whatever else was happening. Although parents acknowledged they had to be adaptable, it was also important for parents to create a new routine and sense of stability as soon as they were able to, to support their functioning as a family. Parents' stories also highlighted that in moments of adversity, sometimes humour was a source of respite. This was evident in the interviews, where parents often laughed as they reflected on serious and traumatic moments along the journey that they were now able to look at in a different way.

Although parents did not draw on religion or spirituality directly, some parents attribute looking at the bigger picture and having a new perspective on what mattered in life as a way of coping.  Across all of the parents' 'narratives focused on their child's survival which linked to a sense of perspective and gratitude that their child's is here and alive and thriving. Many of the parents recognised that they had changed for the better as a result of what they had been through, with a new set of priorities and sense of empowerment. As the parents talked about their children and what they had overcome, it was evident that they viewed the child's illness as only one part of who they are.

### *5.6.3.1 Resilient Children*

The narratives around the children recognised that children can overcome and develop strengths as a result of challenging situations; congruent with evidence that people can experience PTG following trauma (Rodríguez-Rey & Alonso-Tapia, 2019).  Parents are recognised as central to fostering a child's resilience as they support the child to develop adaptive systems that they can use to face challenges (Masten, 2018).Within the literature, it was evident that the parent-child relationship was important in the recovery journey (Egberts et al., 2020; Foster et al., 2019; 2020). This is recognised in the current findings, as children's resilience was attributed to their individual characteristics and the interactions they have with their family. Parents' recognised the importance of portraying the illness in a positive light, with a focus on what the child had overcome. One of positive changes included in PTG is a sense of personal strength, as individuals recognise that as they survived something traumatic, they must be strong (Calhoun & Tedeschi, 2006). Similar findings were reported in the literature (Foster et al., 2020; Jones et al. 2021). Therefore, the parents' narrative around their children as having survived, likely impact on their view of themselves and their ability to face adversity in the future. This highlighted how parents are able to create the children's resilience through the stories they tell, with a focus on what they have overcome. This was particularly evident in Rachel's narrative as she described that Charlie will approach difficult situations with a sense of determination, which she attributes to the fact he has had to face numerous challenges in his past.

### *5.6.4 The Meso-system*

The mesosystem is of particular relevance, as it refers to the relationships between the child, their school and their family. Parents recognised the importance of support from their wider network to help them manage, aligned with the communication and organisation processes in the FRF (Walsh, 2016). The literature recognised that the wider context can exacerbate how stressful an experience is, and continues to be, for example if there is unclear information and a lack of access to services and support (Foster et al. 2020; Jones et al. 2020; McKevitt et al., 2018; Wray et al., 2018).

Families' sought organisational and social support from family and friends throughout the journeys. Laura reflected on how important it was to draw on her support network during the treatment phase, when they were unable to manage the logistics of managing their home lives amidst the appointments and hospital visits. Two parents recognised how important it was for them to be around other families going through the same things as them, as a way of coping with the adversity. Critical childhood illness is rare compared to other conditions which are present in school (McKevitt et al., 2018). Therefore, it can be an isolating experience for families without access to others in the same situation.

#### *5.6.4.1 Medical Support and Relationships with Professionals*

Parents' narratives also highlight that their interactions with health personnel shaped their experiences. This may be in part due to the power held by medical professionals. Across the literature, it was reported that parents value medical advice and professional involvement particularly when faced with uncertainty about their child's illness and recovery trajectory (Jones et al, 2021; McKevitt et al. 2018; Wray et al., 2018). In the current study, it was evidently important for parents to have a clear understanding of what was happening to cope throughout their journey, not only at the diagnosis and treatment stage, but also post-discharge.

The extent to which parents felt involved in their child's care and decision making process impacted on how their stories portrayed their involvement with medical professionals. Parents in the present study described how during the acute phase, their experiences were positive as they were involve in their child's care. Rolland and Walsh (2006) recognise the importance of involving families in this way to provide a sense of mastery for parents; a key component of the FRF. Parents described how the professionals in hospital were containing and communicated in a way that meant they trusted them to look after their children.

Across the literature, findings suggest that although the inpatient care was supportive, once families were discharged, they felt lost and were not given sufficient information which caused feelings of frustration and isolation (Jones et al., 2021; McKevitt et al., 2018; Wray et al., 2018). Although parents in the current study did not describe a sense of isolation, Rachel experienced frustration as she did not receive appropriate professional support regarding her son’s cancer treatment or support with caring for him at home. The anxiety of having to administer medication was not only a new experience, but one that was very distressing, which meant the family relied on charity services to provide the organisational and communication support that they needed to function.

Akin to the literature, parents’ experiences of post-discharge support were inconsistent. Alison recognised that she has received positive supporting ongoing care, in which she values the relationships she has with Adam’s doctors. This may be attributed to the severity of his ongoing care needs, in which Alison has regular contact with the hospital. As in contrast, for parents where the child has physically recovered, parents felt as if they were left to fend for themselves, which added to the stress. This finding also suggests there is still an assumption that once a child recovers physically, the family are not in need of any psychosocial support. This is significant as the literature recognises that parents psychological and social needs are important once home, as they are in survivor mode in the acute phase (Atkins et al. 2012). All of the parents in the current study acknowledged that they were not offered any psychological support. This recognises a systemic issue addressed previously, that there are not clear systems in place to support children and their families (Colville, 2021).

#### *5.6.4.2 Schools*

The current research, recognised the role that schools play in providing support for families. It was important for all of the parents that their child’s school was aware of what they had been through so they could offer support as appropriate. The teachers also recognised that with age, the children’s understanding may change, so it was important to be mindful and informed. Open communication between schools and parents was evident across the stories and this was welcomed by parents. Having a supportive school, where open communication and their child’s needs were taken seriously was evidently a protective factor for families. The findings of the current study were contrasting to the literature where parents struggled to access support at school (Jones et al. 2022; McKevitt et al. 2018).

### *5.6.5 Exo-system and Macro- system*

The exo-system refers to the broader systems which a child or family do not actively engage with, but are still effected by. The lack of inconsistent access to appropriate support services recognised in the literature and the current study may be attributed to a lack of clear policy and guidance. As previously mentioned, there are not clear guidelines for the ongoing needs of children following critical care in comparison to adult populations (NICE, 2009).

The macro-system level, refers to the cultural and historical context within which a child lives, including the underlying ideologies and belief systems. In terms of surviving childhood illness, there is still a focus on a child's recovery as measured by how they are able to function physically and that once a child has recovered physically, they are okay. This is partly due to most research being conducted in the medical fields where there is a focus on such outcome measures (Manning et al., 2018). As the research in Chapter 2 recognises, there is a shift towards considering the child's psychosocial needs. However, this has not necessarily translated into consistent post-discharge support (Atkins et al., 2020; Colville, 2021).

## 5.7 Sharing information: Communication and Understanding

Children drew on specific memories and significant moments when talking about hospital, including specific medical equipment or interactions with their family. These specific memories may have been more significant for the children as they helped them to provide context and a concrete point of reference. However, the way children spoke about their past was evidently influenced by the stories told about them, due to their age at the time.

Within the children's stories, it was notable that there were large gaps in their understanding and memories. As a way of handling the 'unknown and uncertainties' about their experiences, children took memories, that were not theirs and incorporated these into their stories. Both Charlie and David described on moments that were explained to them by their parents, even recognising that they remembered these events because they were told about it. This highlights how reality is created for young children by what they are told. Amidst the adversity and stress of the situation, parents were able to create the memories and context for the children to understand what has happened.

In Charlie's narrative, his identity as a survivor resonates across contexts: at school he compares himself to others with cancer recognising that he is lucky to be here. The narratives about and told by Charlie himself, illustrate that he is continuing to construct an understanding of how his experiences fit into the bigger picture, as he considers what it means to be a Hindu and comes to realise the contrast between survival and death.

Whereas in stories about Ben, it is evident that the narrative around his illness may be overwhelmed by the story of his brother's death, and his position as a survivor is not so prominent. At school, it appears that the focus is not on what he experienced, as a Ben is less inclined to talk about what he has been through, instead focusing his narrative on his brother and their experiences together. These findings highlight how complex it is as children develop an understanding of their experiences when they are equipped with the language and cognitive understanding to process them. For Ben, as recognised by both his mother and teacher, he is continuing to develop his identity and his current narrative may be related to why he survived and his brother did not.

The current findings highlight that the way teachers viewed and came to understand childhood CI that occurred before the children started school, is related to what parents choose to share. The context is also important in how much teachers come to understand, for example, if the children had older siblings at the school when they became unwell. The teachers' stories recognised that the children had been through a serious event. However this was portrayed to varying extents, which can be attributed to how much the parents discuss the illness with school and how much the child also tells their story. However there was also an element of their own personal views of illness that impacted on how they told their story about the child. For example, Sarah reflected on her emotional response to Charlie talking about his illness as he is so young.

Whilst considering that teachers only knew what was shared with them, the researcher reflected on government legislation which stipulates: “parents should provide the school with sufficient and up-to-date information about their child’s medical needs. They may in some cases be the first to notify the school that their child has a medical condition” (DfE, 2015, p.13). However, if there are ongoing care needs; “healthcare professionals, including GPs and paediatricians, should notify the school nurse when a child has been identified as having a medical condition that will require support at school.” (DFE, 2015, p.14). Within the current study this was the case for all families, where the responsibility fell on parents, except for in Adam’s case. This is congruent with findings in the literature (McKevitt et al., 2018; Jones et al, 2022). Both studies recognised the return to school was challenging for parents as they had to educate staff on the nature of their child’s illness and the implications, particularly when they were not visible.

### 5.8 The Future

The stories, although mostly focused on the past and present, did also look forward to the future. Mostly, this was related to ongoing medical check-ups and the importance of being vigilant as their children’s health status may change. The future was particularly prominent for Alison as her narrative illustrated her concerns regarding the potential stigmatisation of Adam’s physical differences, and the impact this could have on his sense of identity and wellbeing.

When the children created their timelines, they were focused on what they like to do and how this defines who they are, even talking about what they hoped to do in the near future. This recognises that for children, although their illness is potentially significant and enduring, it is only one aspect of who they are.

All of the adults’ stories recognised that as the children develop, their cognitive understanding is changing. Therefore, it was recognised that they need to be mindful of whether the child will be adversely affected in the future if they find it distressing to think about the severity of what happened to them.

### 5.9 How parents' helped their child to understand their experiences

In this study, parents held the story of what happened to the children during their CI and therefore the way that the children understand their experiences, is shaped by what their parents shared with them. Sherwin & O'Shanick (1998) propose that children's development of self and identity is constructed by their interactions with others and therefore, the way young children discuss their condition with their family and others represents how they see themselves. Parents' narratives exemplify that they wanted to create a positive narrative and view of the past, for example focusing on the fact the child survived and overcame the illness or that the child is unique and special as a result.

As Adam has an obvious physical differences in his appearance, Alison acknowledged that she wants to celebrate and normalise these. Research recognised that children who had experienced burns (Egberts et al., 2020) found looking at pictures of their past helpful to process what had happened to them. Both Alison and Laura used pictures as a way of explaining and exploring what happened to help their children understand.

Laura reflected that the narrative around Ben is intertwined with the experiences with his brother. Therefore, the process of creating meaning with Ben is complicated by the fact he survived and his brother didn't. Laura recognised that this makes it more difficult to talk about and revisit his CI. However, similar to other parents, she recognised the importance of being honest and open, using age appropriate language and following the child's lead regarding how much they spoke about it.

During Charlie's session, his mother Rachel was present. As a result, the researcher was able to draw on the way that the process of constructing meaning is ongoing between parents and their children. During the interview, Rachel followed Charlie's lead as he spoke, only commenting and offering clarity when Charlie seemed unsure and looked towards her. Rachel was able to fill the gaps in Charlie's narrative, for example when talking about why his hair fell out. Filling a child's gaps in understanding was identified as important in the literature, as children are thought to experience distress if they are confusion about their illness (Atkins et al., 2012;2020; Manning et al., 2017).

The stories in the current study recognise that the children are in a constant process of constructing an understanding with their families. Parents did not want their illness to dominate the child's view of themselves, but also recognised the importance of the children having their own story to tell. All of the children have had some ongoing medical needs or check-ups related to their CI and parents recognised that therefore it was important that they were aware. Rolland and Walsh (2006) recognise the importance of clarifying information and being truthful when communicating with children about their illness, recognising that they need to understand what has happened to them to process it and move on. It is likely that for parents, being able to create a positive narrative with their children was also important for their own emotional recovery. As research suggests, it is important for families to construct a narrative around what happened (Carnevale, 1997; Atkins et al., 2012; 2020).

### 5.10 Reflexivity

This section will be written in first person as the researcher reflects on their experience of the research process. It is important to acknowledge the emotive topic that is childhood CI. During the interviews with parents, it was remarkable to hear how resilient and optimistic they were as they recalled events which had evidently been traumatic at the time. I was aware of my position as a researcher, being privy to their family experiences. I tried to make them feel comfortable by addressing my role and reiterating the purpose of the interview. I also drew upon the principles of attunement. During the sessions with children, I was also struck by how much they had overcome and hearing a child talk about himself a as 'survivor' was also a poignant moment. I was able to attune to participants during the interviews and I got a sense of the emotional difficulties they had experienced. As mentioned in Chapter 1, I have a personal connection to children who have experienced CI in their early years and therefore was particularly mindful of my interpretations of the research.

I reflected regularly on my feeling and thoughts throughout the research and used a reflective diary to document my thoughts. I found this particularly helpful during data collection and analysis. I also checked in regularly with my research supervisor to reflect on any decisions that I made and to discuss and explore my findings. During the re-storying phase, I was mindful of what to include from the parents' narratives, reflecting that their journeys were so rich and eventful that I wanted to do them justice. All of the parents offered their feedback on their stories. Several of the parents felt it had been therapeutic and cathartic to tell their story and then read a summary of their experiences.

### 5.11 Trustworthiness of the Current Research

Within qualitative research it is not possible to apply the same evaluations used in quantative measures, for example validity and reliability (Lieblich et al. 1998). In regards to validity, Braun & Clarke (2013) propose that 'trustworthiness' is an alternative means of judging qualitative methods as the authors recognise that within qualitative research, there are multiple realities. Lincoln and Guba (1985) consider trustworthiness to encapsulate ‘credibility’, ‘transferability’ ‘dependability’ and ‘confirmability’. The researcher will now explore these terms in regards to the current research study.

Dependability and confirmability refer to the process of data collection and design, and ensuring that the study is transparent about how conclusions were made about the data collected.  In Chapter 3, the researcher provided details of the research design and method including how the research was carried out and what data analysis methods were applied. A summary of the research process can also be seen in Appendix W. The researcher has also demonstrated how conclusions were made from the data through the inclusion of examples of the re-storying phase (see Appendix L-O) and identification of narrative themes in the appendix (see Appendix X-AB). Additionally the researchers’ supervisor examined the findings and any conclusions were discussed in supervision.

Credibility is concerned with the extent to which the findings are a ‘true’ representation of the participants’ views (Hannes, 2011). The researcher read the transcripts multiple times and immersed themselves in the data. Additionally, the researcher engaged in member checking with the parents, as a means of ensuring that the stories were an accurate representation of their experiences. Finally, transferability is the degree to which the findings can be generalised to other contexts (Braun & Clarke, 2013). The researcher did not intend to make generalisable claims about the wider population of childhood illness in line with narrative research (Polkinghorne, 2007). However, the research included rich examples of participants within their context, which means that those reading the can determine the extent to which they represent the findings of others in similar populations.

## 5.11 Critique of Current Research

### *5.11.1 Barriers to Recruitment*

The researcher faced multiple barriers to recruitment. Feedback from SENCO's and EP's in the researcher's LA, highlighted that they were not necessarily aware of any children who had experienced CI. It appeared that unless the child had ongoing medical needs, schools are not particularly aware, and parents may not have shared this information with them. This was an interesting reflection for the researcher, and part of the reason they were interested in the research, considering the implications of CI reported in the literature. The researcher also recognised that most of the research in this area is conducted by medical professionals, who have access to participants through their admission to hospital.

Once the research was advertised more widely, parents made contact. It is important to acknowledge that the researcher took an opportunistic sample of parents who were keen to take part. Parents' desire to take part was likely related to the fact it had been many years since their child became unwell, and also that they were in a positive place to share their story. Therefore, it is important to recognise that it does not represent the mothers/parents who may not yet be able to reflect upon their experiences due to the emotive challenges.

### *5.11.2 Participants*

A strength of the study is the inclusion of parents, children and teachers. The researcher, in part to aid recruitment, did not stipulate that there was a specific time since the illness. The children in the current study, had experienced their initial onset of CI at least three years ago, with most of the children not having any ongoing treatment for at least two years. This is important to note, as over time, children and their families have recovered and come to terms with their experiences. Therefore, parents were able to look back on their experiences with a different perspective than if they had been interviewed in the months straight after discharge. Within the literature field, as identified in Chapter 2, the majority of the research in this area is conducted within the first two years, therefore the current study adds to this field by showing how families move on and adapt around the child's illness over time.

An additional strength of the study is the inclusion of young children, who as recognised in the literature, are largely excluded from research in this area. Therefore, the research offers insight into how young children talk about their CI which occurred at a time when they were unable to make sense and understand what was happening to them**.** The researcher recognises that although they were able to gather the child's voice, it was not at the prevalence hoped for. The researcher was only able to meet each child on one occasion due to difficulties with recruitment and time constraints and this is recognise as a limitation of the study. As a result, the researcher was not able to develop a rapport with the children to the extent she had hoped, nor have time to reflect on whether she need to adopt the data collection methods to suit the communication needs of the children. The researcher also recognises that not all of the children in the study were familiar with retelling the story of their critical illness which likely impacted on the extent to which they were able to communicate with the researcher.

The researcher adapted their ethics to allow for a wider age range and type of illness due to the issues with recruitment. The researcher was initially interested in working with children who were in the Early Years or Reception so that their experience of starting school could be explored. However, most of the children were already in Year 1 at the time of the research. The researcher acknowledged that therefore the considerations made by school when children started could not be explored in depth. However the research still adds value to the area of early childhood CI in education by exploring how this experiences are understood by teachers.

The children represent the diversity of children admitted to PCC in the UK as they included unplanned respiratory, complex needs and planned neurological surgery (NHS, 2017). The researcher acknowledges that half of the sample were children who had cancerous brain tumours and underwent chemotherapy in addition to surgery and one child had a range of complex medical needs as a result of being premature. The researcher recognised that within the papers included in the literature in Chapter 2, there were a wide range of illnesses and ages included, including children who had pre-existing medical conditions and neurological conditions. Nevertheless, any conclusions taken from this study should be cautiously generalised to the wider population of children who have experienced critically illness in early childhood.

The sample lacked diversity which is a limitation as the way that parents make sense and come to terms with their experience may be influenced by cultural beliefs and religion (Atkins et al., 2012). Additionally, all of the parents were mothers and all of the children were male. Therefore the findings can only be considered an exploration of the experiences of mothers, and male children who have experienced CI.

#### *5.11.2.1 Parental consent*

One of the children's parents did not wish for them to take part due to the particular family context, and the loss of his older brother. The parents felt it would not be appropriate for the child to speak with the researcher about their illness and experiences. While the researcher intended to recruit a child, parent and teacher for each case, this was not a limiting factor. The researcher made the decision to still include both the parent and teacher, as they wanted to tell their story and the researcher felt they could still gain insight from the parents' recollection, particularly as parents of young children with CI held the main narrative of the events. Additionally, the researcher reflected on their ethical duty as a researcher (respecting parents' knowledge of their child) and recognised that it may not have been helpful to the child to have taken part. In this case, the parents recognise the child is still coming to terms with this loss and developing an understanding about what happened. When doing research with young children it is accepted that there are likely be issues surrounding consent and participation as the parents are gatekeepers to whether children are able to take part in the first instance. The researcher recognised that had the additional child taken part, it may have provided further insight into what stories young children tell about their CI, yet the mother and teacher were able to offer great insight into how the child's understanding continues to be constructed with the parents.

### *5.11.3 Online Sessions*

The impact of Covid-19 meant that the researcher conducted some data collection online and this was both a challenge and an opportunity. The researcher was able to offer flexibility to parents about how they took part and this did aid recruitment once it was advertised online. Both the researcher and participants recognised they were used to remote working which meant that they felt comfortable interviewing in this way. The researcher acknowledged that using both online and in-person data-collection methods likely impacted on how the stories were constructed. Although giving participants the choice, meant that they were more comfortable with the context of the interviews.

Additionally, the session with Charlie was also conducted online with his parent present. The researcher reflected that the online process made it difficult as she could not see and comment on his timeline drawing easily. The researcher felt this session would have been easier in person. In addition, the presence of his mother meant that he may have contributed in a different way. However, Rachel's presence in the interview aided his recollection of his experiences as he turned to her when unsure, and she was able to encourage him. Although this could be considered a limitation as the data gathered was co-constructer not only by the researcher and the child, it also provided insight into how parents support their children to formulate their own understanding of their experiences.

## 5.12 Implications for Practice

### *5.12.1 Further Research*

The literature in this field was focused on specific time points in the first two years following discharge from hospital, whilst this current study looked at families' experiences years later. As evidence suggests that individual are at risk of PTSS and medical trauma as they realise the severity and face the fact they may have died (Colville & Pierce, 2012; Kazak et al., 2006), it is possible that children will continue to need support to reconcile these challenges as they develop an understanding of what this means. Therefore, more longitudinal research would be helpful to recognise how children and their families psychosocial needs change over time. The participants in the current study may have told a different story had they been interviewed in the past or the future.

As the researcher had initially planned, it would be helpful to conduct further research with the same groups in regards to children who have experienced CI in the early years, as they start at school or nursery. This would allow further investigation about what sort of support would be most helpful in that period and also how they find the adjustment to school. It may also be helpful to consider research which includes professionals from both health and education services, to develop a better understanding of how children who have experienced CI are supported post-discharge, and whether these services could be improved, particularly as children start school.

### *5.12.2 Implications for Supportive Aftercare*

Several shared themes across the stories emerged that recognise the importance of access to support services and that consistent, accessible and coordinated care is valued by families. As mentioned, there are not clearly defined systems of supporting children and their families in the community once physically recovered and discharged from hospital (Colville, 2021; DfE, 2015). Therefore, this study adds to the literature recognising the importance of coordinated care in the community that considers the family’s psychosocial needs over time.

Walsh (2021) recognises that although families can demonstrate resilience and draw on their own personal resources, as they did in the current study, this should be interpreted with caution. Services should still be available to provide ongoing support. This support should also help families to recognise what strengths and resilience factors that have to support them and recognise that there is not a universal approach that suits all families so there is need to be flexible and family led.

There is growing evidence for the value of using diaries to help aid memory and understating post-discharge from PICU (Mikkelsen, 2018) for families and children. As evidenced in the current study, having a story to tell was important for children as they drew on their parents memories to create a coherent narrative when they did not have the understanding. Therefore, children would likely benefit from opportunities to look back on their experiences and engage in life story work about what happened to them as they continue to develop. This would allow children to recognise what happened, what they have overcome and what this means for them.

### *5.12.3 Implications for EPs*

EPs are well positioned to bridge the gap between health and education due to their position on the 'outside' of systems. EPs have regular contact with schools and are well placed to support ongoing monitoring of children, and any provision that is put in place. The current study recognises that there is not clear guidance between health and education about children who have experienced CI. The researcher acknowledges that it is important that parents have the choice to tell school and disclose information as they wish. However, the current research highlights that parents valued staff being aware. This does not necessarily mean that children who have experienced CI will need additional support, but parents value school being able to respond sensitively and offer support where appropriate. As Laura recognised, her child can become distressed by things that are innocuous to others. Therefore, it is important that people are aware and there is a joined up and consistent approach to support. As recognised throughout the literature, children are susceptible to a range of psychosocial adversity as a result of experiencing critical illness. Although this was not a prominent issue in the current sample, parents recognised that their children are continuing to develop an understanding and therefore it may be that as they grow older, they will benefit from ongoing space and time to explore their experiences and may need psychological support as appropriate. EPs are well positioned to collaborate with parents and schools to support with implementing and offering this support as appropriate.

This study contributes to the growing body of research promoting the use of narrative methods in work with children and parents. The current research supports the notion that creating a narrative, can be therapeutic and helpful for parents. Therefore, it supports the notion that narrative approaches should be used in work with families and children in EP practice. As by reflecting on their past and constructing a narrative, individuals are able to make sense of their past and draw on their own strengths and resources.

A key reflection from the current research is the power that adults have regarding how a child develops an understanding of their experiences. This has implications for school practice, as the language used with children can shape how they view themselves. Therefore there are implications for how staff talk with children about their experiences. This can help to foster resilience by focusing on their strengths and what they have overcome whilst also providing space to reflect on the challenges as appropriate.

In summary, implications for EP practice include:

- Narrative work with children, including young children, to explore their sense of identity and understanding
- Narrative work with parents to make sense of their experiences and draw on their own strengths and resources
- Liaison between health and education services (e.g. attending Team around the Child meetings with multidisciplinary professionals)
- Supporting both school professionals and parents to reflect upon the language they use with children to develop their sense of identity around CI at an age appropriate level
- Work with schools and families to consider what is important to monitor when children have experienced CI

### 5.13 Final Conclusions

This is an under researched area, arguably because it is not clear what impact there is or how much young children do understand at about CI. The current findings illustrate that children and families who have experienced critical illness are able to adapt and manage the adversity. It is evident that that young children who have experienced CI in the preschool years construct an understanding based on the narratives of their parents. It also can be concluded that both children and families need to make sense of their experiences and children need to understand what happened to them and that this evolves over time. The current findings recognise that children, who experienced CI in their early years, are developing an identity around these experiences. As they grow and develop, these experiences will likely continue to form part of who they are.

## References

Abela, K. M., Wardell, D., Rozmus, C., & LoBiondo-Wood, G. (2020). Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review. *Journal of Pediatric Nursing*, *51*, 21–31. https://doi.org/10.1016/j.pedn.2019.10.013

Andrews, T. (2012). What is social constructivism? *Grounded Theory Review: An International Journal, 11*(1). http://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/

Association of Educational Psychologists (AEP). (2020). *Working Remotely with Children, Young People and their Families: Staying safe, maintaining data security, upholding professional standards and using technology.* https://business.senedd.wales/documents/s102276/CYPE%20COV%2075b%20-%20Association%20of%20Educational%20Psychologists%20AEP%2018%20May%202020%20Published%2017%20June%202020.pdf

Atkins, E., Colville, G., & John, M. (2012). A ‘biopsychosocial’ model for recovery: A grounded theory study of families’ journeys after a Paediatric Intensive Care Admission. *Intensive & Critical Care Nursing*, *28*(3), 133–140. https://doi.org/10.1016/j.iccn.2011.12.002

Atkins, E., John, M., & Colville, G. (2020). Families’ experiences of life in the year after a child’s critical illness: Navigating the road to a “New Normal”. *Journal of Pediatric Intensive Care*, *09*(3), 188–195. https://doi.org/10.1055/s-0040-1705132

Bagnoli, A. (2009) Beyond the standard interview: The use of graphic elicitation and arts-based methods. *Qualitative Research 9*(5), 547-570. https://doi.org/10.1177/1468794109343625

Bamberg, M. (2011). Who am I? Narration and its contribution to self and identity. *Theory & Psychology, 21*(1), 3–24. https://doi.org/10.1177/0959354309355852

Bell, J. S. (2002). Narrative inquiry: More than just telling stories. *TESOL Quarterly*, *36*(2), 207–213. https://doi.org/10.2307/3588331

Becker, G. (1997). *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press. https://doi.org/10.1525/9780520919242

Betchley, D., & Falconer, W. (2002). Giving Colin a voice: The challenge of narrative therapy with a client who has an intellectual disability and communication difficulties. *Australian Social Work*, *55*(1), 3–12. https://doi.org/10.1080/03124070208411667

Booth, A., Sutton, A., & Papaioannou, D. (2016). *Systematic approaches to a successful literature review.* (2nd ed.). SAGE.

Booth, T. & Booth, W. (1996) Sounds of Silence: Narrative research with inarticulate subjects. *Disability & Society, 11*(1), 55-70. https://doi.org/10.1080/09687599650023326

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE.

British Psychological Society (BPS). (2018). *Code of ethics and conduct.* https://www.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Harvard University Press.

Bruner, J. (1991). The narrative construction of reality. *Critical Inquiry*, *18*(1), 1-21. http://dx.doi.org/10.1086/448619

Calhoun, L., & Tedeschi, R. (2006). The foundations of posttraumatic growth: An expanded framework. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 3-23). Erlbaum.

Carnevale F. A. (1997). The experience of critically ill children: narratives of unmaking. *Intensive & Critical Care Nursing*, *13*(1), 49–52. https://doi.org/10.1016/s0964-3397(97)80733-1

Carr, D. (1986). Narrative and the Real World: An Argument for Continuity. *Journal of historical studies*. https://doi.org/10.2307/2505301

Carter, B. and Ford, K. (2013) Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Research in Nursing & Health 36*(1), 95-107. https://doi.org/10.1002/nur.21517

Clandinin, D., & Connelly, M. (2000). *Narrative inquiry: Experience and story in qualitative research.* USA: Jossey-Bass.

Clark, A. (2017). *Listening to young children, expanded third edition: A guide to understanding and using the mosaic approach*. Jessica Kingsley Publishers.

Coad, J. (2007) Using art-based techniques in engaging children and young people in child research. *Journal for Specialists in Pediatric Nursing, 71* (1), 3-9. https://doi.org/10.1177/1744987107081250

Colville, 2021. *The Psychological Impact of Admission to Intensive Care.* [Doctoral thesis, Goldsmiths University of London.] Research Online. https://research.gold.ac.uk/id/eprint/31178/

Colville, G., & Pierce, C. (2012). Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Medicine*, *38*(9), 1523-1531. https://doi.org/10.1007/s00134-012-2612-2

Creswell, J. W., & Creswell, J. D. (2018). *Research design : qualitative, quantitative & mixed methods approaches* (5th ed.). SAGE.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches.* (4th ed). SAGE.

Critical Appraisal Skills Programme. (2018). *CASP qualitative studies checklist.* https://casp-uk.net/casp-tools-checklists/.

Crossley, M. (2007). Narrative analysis. In Lyons, E., & Coyle, A. (Eds.), *Analysing qualitative data in psychology* (pp. 131-144). SAGE. https://www.doi.org/10.4135/9781446207536

Crossley, M. L. (2000). *Introducing narrative psychology: Self, trauma, and the construction of meaning.* Open University Press Buckingham.

Czarniawska, B. (2004). *Introducing qualitative methods: Narratives in social science research*. SAGE. https://dx.doi.org/10.4135/9781849209502

Denzin, N. & Lincoln, Y. (2005). Introduction: the discipline and practice of qualitative research. In Denzin, N. and Lincoln, Y. (Eds.), *Handbook of Qualitative Research* (pp. 1-17). SAGE.

Department for Education (2015). *Supporting pupils at school with medical conditions.* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

Department for Education. (2021). *Statutory framework for the early years foundation stage Setting the standards for learning, development and care for children from birth to five.* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/974907/EYFS_framework_-_March_2021.pdf

Dewey, J. (1963). *Experience and education*. Collier.

Dow, B., Kenardy, J., Long, D., & Le Brocque, R. (2012). Children's post-traumatic stress and the role of memory following admission to intensive care: A review. *Clinical Psychologist, 16*(1), 1–14. https://doi.org/10.1111/j.1742-9552.2012.00040.x

Driessnack, M., & Furukawa, R. (2012). Arts-based data collection techniques used in child research. *Journal for Specialists in Pediatric Nursing*, *17*(1), 3-9. https://doi.org/10.1111/j.1744-6155.2011.00304.x

Earthy, S., Cronin, A. (2008). Narrative analysis. In N. Gilbert (Ed.), *Researching social life* (3rd ed., pp. 420–439). SAGE.

Egberts, M. R., Geenen, R., De Jong, A. E., Hofland, H. W., & Van Loey, N. E. (2020). The aftermath of burn injury from the child’s perspective: A qualitative study. *Journal of Health Psychology*, *25*(13/14), 2464–2474. https://doi.org/10.1177/1359105318800826

Ekim, A. (2020). The post-intensive care syndrome in children. *Comprehensive child and adolescent nursing*, *43*(1), 15-21. https://doi.org/10.1080/24694193.2018.1520323

Engel, G. (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196,* 129-36.

Engel, S. (2005). Narrative analysis of children’s experience In S. Greene & D. Hogan (Eds.) *Researching Children’s Experiences: Approaches and methods* (pp.199-216). SAGE.

Fayed, N., Cameron, S., Fraser, D., Cameron, J. I., Al-Harbi, S., Simpson, R., Wakim, M., Chiu, L., & Choong, K. (2020). Priority outcomes in critically ill children: A patient and parent perspective. *American Journal of Critical Care*, *29*(5), 94-103. https://doi.org/10.4037/ajcc2020188

Flewitt, R (2005). Conducting research with young children: some ethical considerations. Early Child Development and Care, 175(6), pp. 553–565. https://doi.org/10.1080/03004430500131338

Foster, K., Mitchell, R., Young, A., Van, C., & Curtis, K. (2019). Parent experiences and psychosocial support needs 6 months following paediatric critical injury: A qualitative study. *Injury*, *50*(5), 1082–1088. https://doi.org/10.1016/j.injury.2019.01.004

Foster, K., Van, C., McCloughen, A., Mitchell, R., Young, A., & Curtis, K. (2020). Parent perspectives and psychosocial needs 2 years following child critical injury: A qualitative inquiry. *Injury*, *51*(5), 1203–1209. https://doi.org/10.1016/j.injury.2020.01.017

Foucault, M. (2002). *Archaeology of Knowledge*. (2nd ed). Routledge. https://doi.org/10.4324/9780203604168

Guba, E & Lincoln, Y, (1994) Competing paradigms in qualitative research. In N.K.Denzin & Y.S. Lincoln. (Eds.), *Handbook of Qualitative Research (*pp.105-117). SAGE.

Hannes, K. (2011). Chapter 4: Critical appraisal of qualitative research. In *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.* http://methods.cochrane.org/qi/sites/methods.cochrane.org.qi/files/uploads/Chapter_Guidancecritical_appraisal.doc

Health and Care Professions Council (HCPC). (2016). *Standards of conduct, performance and ethics*. https://www.hcpc-uk.org/globalassets/resources/standards/standards-of-conduct-performance-and-ethics.pdf

Jones, S., Tyson, S., Davis, N., & Yorke, J. (2020). Qualitative study of the needs of injured children and their families after a child's traumatic injury. *BMJ Open*, 10, Article e036682. http://dx.doi.org/10.1136/bmjopen-2019-036682

Jones, S., Tyson, S., Davis, N., & Yorke, J. (2021). The impact of injury: The experiences of children and families after a child's traumatic injury. *Clinical Rehabilitation*, *35*(4), 614–625. https://doi.org/10.1177/0269215520975127

Jones, S., Tyson, S., Davis, N., & Yorke, J. (2022). Educational support needs of injured children and their families: A qualitative study. *Journal of Rehabilitation Medicine*, *54,* Article jrm00246. https://doi.org/10.2340/jrm.v53.710

Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M. A., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology, 31*(4), 343-355. https://doi.org/10.1093/jpepsy/jsj054

Keeble, E. & Kossarova, L. (2017) *Focus on: Emergency hospital care for children and young people. QualityWatch.* The Health Foundation and the Nuffield Trust. https://www.nuffieldtrust.org.uk/research/focus-on-emergency-hospital-care-for-children-and-young-people

Kincheloe, J. (2004) ‘Foreword’, in L. D. Soto and B. B. Swadener (Eds*). Power and Voice in Research with Children*, pp. xi--xiv. Peter Lang.

Kornbluh, M. (2015). Combatting challenges to establishing trustworthiness in qualitative research. *Qualitative Research in Psychology, 12*(4), 397- 414. https://doi.org/10.1080/14780887.2015.1021941

Kramp, M. K. (2004). Exploring life and experience through narrative inquiry. In K. De Marrais & S. D. Lapan (Eds.) *Foundations for research: Methods of inquiry in education and social Sciences* (pp. 103–122). Lawrence Erlbaum Associates.

Lerret, S. M., Johnson, N. L., & Haglund, K. A. (2017). Parents’ perspectives on caring for children after solid organ transplant. *Journal for Specialists in Pediatric Nursing*, *22*(3) 1-8. **https://doi.org/10.1111/jspn.12178**

Lewis, J., P. (2014). Narrative research. In J. Mills, & M. Birks. (Eds). *Qualitative* Methodology*: A Practical Guide* (pp.161-179). SAGE. https://dx.doi.org/10.4135/9781473920163.n10

Lewis, K,M., Parekh, SM., Ramnarayan, P., Gilbert, R., Hardelid, P. & Wijlaars., L. (2020) Emergency paediatric critical care in England: describing trends using routine hospital data. *Archives of Disease in Childhood, 105*(11) 1061-1067. http://dx.doi.org/10.1136/archdischild-2019-317902

Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative research: reading, analysis and interpretation.* SAGE.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry.* SAGE.

Locatelli, M. G. (2020). Play therapy treatment of pediatric medical trauma: A retrospective case study of a preschool child. *International Journal of Play Therapy, 29*(1), 33–42.

https://doi.apa.org/doi/10.1037/pla0000109

Lupton, D. (2003). *Medicine as Culture: Illness, Disease and the Body in Western Societies.* (2nd Ed.). SAGE.

Manning, J. C., Hemingway, P., & Redsell., S. A. (2017). Stories of survival: Children's narratives of psychosocial well-being following paediatric critical illness or injury. *Journal of Child Health Care*, *21*(3), 236–252. https://doi.org/10.1177/1367493517717078

Manning, J. C., Pinto, N. P., Rennick, J. E., Colville, G., & Curley, M. (2018). Conceptualizing Post Intensive Care Syndrome in Children-The PICS-p Framework. *Pediatric critical care medicine: a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*, *19*(4), 298–300. https://doi.org/10.1097/PCC.0000000000001476

Masten, A.S. (2018), Resilience Theory and Research on Children and Families: Past, Present, and Promise. *Journal of Family Theory & Review, 10,* 12-3. https://doi.org/10.1111/jftr.12255

McAdams, D. P. (1993). *The stories we live by: Personal myths and the making of the self.* Guilford Press.

McAlpine, L. (2016). Why use narrative? A story about a narrative. *Estonian Journal of Education. Estonian Journal of Education*, *4* (1), 32-57. https://doi.org/10.12697/eha.2016.4.1.02b

McIntosh, C., & Stephens, C. (2012). A storybook method for exploring young children's views of illness causality in relation to the familial context. *Early Child Development and Care*, *182*(1), 23-33. https://doi.org/10.1080/03004430.2010.534161

McKevitt, C., Topor, M., Panton, A., Mallick, A. A., Ganesan, V., Wraige, E., & Gordon, A. (2019). Seeking normality: Parents' experiences of childhood stroke. *Child: Care, Health & Development*, *45*(1), 89–95. https://doi.org/10.1111/cch.12622

Mertens, D. M. (2007). Transformative Paradigm: Mixed Methods and Social Justice. *Journal of Mixed Methods Research*, *1*(3), 212–225. https://doi.org/10.1177/1558689807302811

Mikkelsen G. (2018). The meaning of personal diaries to children and families in the paediatric intensive care unit: A qualitative study. *Intensive & critical care nursing*, *45*, 25–30. https://doi.org/10.1016/j.iccn.2017.10.001

Murray, M. (2015). Narrative Psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (3rd ed., pp. 85-107). SAGE.

Nasheeda, A., Abdullah, H. B., Krauss, S. E., & Ahmed, N. B. (2019). Transforming Transcripts Into Stories: A Multimethod Approach to Narrative Analysis. *International Journal of Qualitative Methods*, *18*, 1-9. https://doi.org/10.1177/1609406919856797

National Health Service (2017). *Paediatric critical care and specialised surgery in children review. NHS England.* https://www.england.nhs.uk/wp-content/uploads/2017/06/paeds-review-demand-capacity-analysis-v1-5.pdf

National Institute for Health and Care Excellence (2009). *Rehabilitation after illness in adults*. [NICE Guideline No. 83]. https://www.nice.org.uk/guidance/cg83/resources/rehabilitation-after-critical-illness-in-adults-pdf-975687209413

Nelson, K., & Fivush, R. (2004). The emergence of autobiographical memory: a social cultural developmental theory. *Psychological review*, *111*(2), 486-511. https://doi.org/10.1037/0033-295X.111.2.486

Ollerenshaw, J. A., & Creswell, J. W. (2002). Narrative research: A comparison of two restorying data analysis approaches. *Qualitative Inquiry*, *8*(3), 329–347. https://doi.org/10.1177/10778004008003008

Paediatric Intensive Care Audit Network. *Paediatric Intensive Care Audit Network Annual Report 2021* (published January 2022): Universities of Leeds and Leicester. https://www.picanet.org.uk/wp-content/uploads/sites/25/2022/01/PICANet-2021-Annual-Report_v1.0-13Jan2022-2.pdf

Paediatric Intensive Care Society. *Quality Standards for the Care of Critically Ill Children.* (published December 2015). https://pccsociety.uk/wp-content/uploads/2016/05/PICS_standards_2015.pdf

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*, Article n71. https://doi.org/10.1136/bmj.n71

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, *8*(1), 5–23. https://doi.org/10.1080/0951839950080103

Polkinghorne, D. E. (2007). Validity issues in narrative research. *Qualitative Inquiry*, *13*(4), 471–486. https://doi.org/10.1177/1077800406297670

Rodríguez-Rey, R., & Alonso-Tapia, J. (2019). Predicting posttraumatic growth in mothers and fathers of critically ill children: A longitudinal study. *Journal of clinical psychology in medical settings*, *26*(3), 372-381. https://doi.org/10.1007/s10880-018-9594-3

Riessman, C., Kohler. (2008). *Narrative methods for the human sciences*. SAGE.

Robson, C., & McCartan, K. (2016). *Real world research* (4th ed.). Wiley.

Rolland J. S. (1994). *Families, illness, & disability: an integrative treatment model.* Basic Books.

Rolland, J. S., & Walsh, F. (2006). Facilitating family resilience with childhood illness and disability. *Current opinion in pediatrics*, *18*(5), 527-538. https://doi.org/10.1097/01.mop.0000245354.83454.68

Rubin, H. and Rubin, I. (2005). *Qualitative interviewing: The art of hearing data.* SAGE.

Salmon, K., & Bryant, R. A. (2002). Posttraumatic stress disorder in children: The influence of developmental factors. *Clinical Psychology Review*, *22*(2), 163-188. https://doi.org/10.1016/S0272-7358(01)00086-1

Sherwin, E. D., & O'Shanick, G. J. (1998). From denial to poster child: Growing past the injury. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (pp. 331–343). Butterworth-Heinemann.

Skott, C. (2001). Caring narratives and the strategy of presence: Narrative communication in nursing practice and research. *Nursing Science Quarterly*, *14*(3), 249-254. https://doi.org/10.1177/08943180122108364

Squire, C., Andrews, M., & Tamboukou. (2008). *Doing narrative research.* SAGE.

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: conceptual foundations and empirical evidence. *Psychological inquiry*, *15*(1), 1-18. https://www.jstor.org/stable/pdf/20447194.pdf

Tierney, A. L & Nelson, C. A. (2009). Brain development and the role of experience in the early years. *Zero to Three. 30*, 9–13. https://www.researchgate.net/publication/253336281_Brain_Development_and_the_Role_of_Experience_in_the_Early_Years.

Ungar, M. (Ed.). (2021). *Multisystemic resilience: Adaptation and transformation in contexts of change*. Oxford University Press.

Vygotsky, L.S (1978). Mind in society: The development of higher psychological processes. Harvard University Press.

Walsh F. (2006) *Strengthening family resilience.* (2nd ed). Guilford.

Walsh, F. (2016). Family resilience: A developmental systems framework. *European journal of developmental psychology*, *13*(3), 313-324. https://doi.org/10.1080/17405629.2016.1154035

Walsh, F. (2021). Family resilience. In M. Ungar (Ed.). (2021). *Multisystemic resilience: Adaptation and transformation in contexts of change* (pp. 255-270). Oxford University Press.

Williams, C. N., Eriksson, C., Piantino, J., Hall, T., Moyer, D., Kirby, A., & McEvoy, C. (2018). Long-term sequelae of Pediatric Neurocritical Care: The parent perspective. *Journal of Pediatric Intensive Care*, *7*(4), 173–181. https://doi.org/10.1055/s-0038-1637005

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21*(2), 152-169. https://doi.org/10.1017/S0959259810000420

Wray, J., Brown, K., Tregay, J., Crowe, S., Knowles, R., Bull, K., & Gibson, F. (2018). Parents' experiences of caring for their child at the time of discharge after cardiac surgery and during the post discharge period: Qualitative study using an online forum. *Journal of Medical Internet Research*, *20*(5), Article e155. https://doi.org/10.2196/jmir.9104

# Appendices

## Appendix A: Details of Systematic Search.

| | |
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| Search date | 22.7.21 |
| Database searched through EBSCO | PsychINFO, CINAHL Plus, Academic Search Complete, Child, Development & Adolescent studies. |
| Boolean string searched | (paediatric or child*) AND (experiences or needs or outcomes or effects or impacts or consequences) AND (post discharge or following discharge or after discharge) AND (psychological or social or psychosocial or emotional) AND (illness or injury or ill or "critical care") |
| Results | Total : n=609.<br>PsycINFO: n=161.<br>CINAHL Plus : n=187.<br>Child, Development & Adolescent studies : n=8.<br>Academic Search Complete : n=253. |
| Duplicates removed | n=126 |
| Advanced search inclusion criteria applied | Peer reviewed journals; 2010-2021; English |
| Results | n=305 |
| *Record title and abstract screened for inclusion and exclusion criteria* | |
| Records sought for retrieval | n=22 |
| *Full text screened for inclusion and exclusion criteria* | |

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| Records included in literature review | n=9 |

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| Search date | 22.7.21 |
| Database searched | SCOPUS |
| Boolean string searched | (paediatric or child*) AND (experiences or needs or outcomes or effects or impacts or consequences) AND (post discharge or following discharge or after discharge) AND (psychological or social or psychosocial or emotional) AND (illness or injury or ill or "critical care") |
| Results | n=165 |
| Advanced search inclusion criteria applied | Published, Peer reviewed journals; 2010-2021; English, journal articles. |
| Results | n=97 |
| *Record title and abstract screened for inclusion and exclusion criteria and duplicates from other searches removed* | |
| Records sought for retrieval | n=3. |
| *Full text screen for inclusion and exclusion criteria* | |
| Record included in literature review | n=0 |
| Comments | Many of the papers were focused on medical outcomes or perspective on inpatient treatment. |

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| Search date | 27.7.21 |
| Database searched | PubMed |
| Boolean string searched | ((paediatric or child*) AND (experiences or needs or outcomes or effects or impacts or consequences) AND (post discharge or following discharge or after discharge) AND (psychological or social or psychosocial or emotional) AND (illness or injury or ill or "critical care") |
| Results | n=605 |
| Advanced search inclusion criteria applied | English, 2010-2021, Journal article. Peer reviewed journals. |
| Results | n=388 |
| *Record title and abstract screened for inclusion and exclusion criteria and duplicates from other searches removed* | |
| Records sought for retrieval | n=6 |
| *Full text screen for inclusion and exclusion criteria* | |
| Record included in literature review | n=2 |
| Comments | A lot of duplicates or medical literature. |

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| Search date | 22.7.21 |
| Database searched | Science Direct |
| Boolean string searched | (paediatric or child or childhood or children) AND (experiences or needs or outcomes or effects or impacts or consequences) AND (post discharge or following discharge or after discharge) AND (psychological or social or psychosocial or emotional) AND (injury or illness) |
| Results | n=423 |
| Advanced search inclusion criteria | English, 2010-2021, journal articles, peer reviewed. |
| Results | n=49 |
| *Record title and abstract screened for inclusion and exclusion criteria and duplicates from other searches removed* | |
| Records sought for retrieval | n=1 |
| *Full text screen for inclusion and exclusion criteria* | |
| Record included in literature review | n=1 |
| *Comments* | Cannot use wildcard – change search terms to : paediatric or child or childhood or children. The search string used on other databases resulted in nothing relevant to research area, once removed 'ill or critical care; found relevant papers, although most were duplicates or focused on specific aspects of medical care or outcomes. |

**Appendix B:Critique of papers**

| **Title, Author and Country** | **Research aims and Participants** | **Research Design, Methodology and Theoretical and conceptual underpinnings** | **Key findings and implications** | **CASP** |
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| Jones, S., Tyson, S., Yorke, J., & Davis, N. (2021)<br>The impact of injury: The experiences of children and families after a child's traumatic injury. *Clinical Rehabilitation*, *35*(4), 614–625. | To explore the experiences of children and families after a child's traumatic injury.<br><u>Participants</u><br>Children (n=13) and their parents (n=14). 5 additional parents (of children who did not take part). Mothers n=18) Fathers (n=1) Guardian (n=1). | <u>Qualitative.</u> Semi-structured interviews took place between 1-12.5 months after discharge, avg. 8.5). 26 interviews with 32 participants.<br>Data analysed through thematic analysis.<br>Themes coded for in analysis initially emerged from interview | <u>**Themes & subthemes:**</u><br><u>**Impact of injury:**</u><br>***Physical and cognitive impacts*** (physical impairments, sensory impairments, physical symptoms physical appearance)<br>***Practical impacts***<br><u>child:</u> increased dependence of parents, reduced attendance at school.<br><u>parents:</u> increased care requirements, time off work, adapting work, reliance on others, daily routine disrupted.<br><u>Child and parent:</u> demand of appointments.<br>***Emotional impacts*** | The aim of the research was clear and well positioned in the wider context with a focus on the impact of childhood injury on the child and their family after discharge due to an identified gap.<br>Qualitative methodology appropriate because research aim is to explore the subjective and personal experiences of the participants.<br>Clear discussions of recruitment and purposeful |

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| UK | Criteria: Child discharged over 2 weeks ago, but within 12 months. Included all types of injury with injury score >8,<br>Age: 5-16 years old.<br>No ethnicity or demographic data. | questions topic areas (experiences of health and community services after discharge and the social, emotional physical and practical impact of the injury) which were based on a previous scoping review of the literature.<br>Parent and child data analysed together.<br>No theoretical underpinnings identified. | Child: loss of confidence, boredom, frustration, anger, needing more support needed.<br>Parents: prioritising child before themselves, fear and worry about recovery and future, difficulty watching child suffer, emotional rollercoaster and relief.<br>Child and parent : PTSD, upset, guilt, sadness.<br>***Positive impact***<br>Child : bravery, resilience, determination.<br>Child and parent: new appreciation of life, increased empathy, reassessment of priorities.<br>***Impact of family life***<br>: changed roles in family, increased focus on injured child, reduced contact whilst in hospital.<br>***Social impacts***<br>Child: changed friendships, friendships with injured children, friendship difficulties, hard to make new friends when injured during school transition.<br>Parent : forming bond with parents in similar position<br>**Experience of discharge from hospital and returning home :** -<br>***Adapting to home*** | sampling to cover a range of injury and childhood ages to represent real life admissions to trauma hospitals. Does not provide justification for why they did not include children under 6 or parents of infants under 2 at time of injury.<br>Clear explanation of how participants were recruited through two major trauma centres in England via post – or in person following discharge from hospital.<br>Clear description of how the data was collected via semi-structured interviews and why this approach enabled researchers to address research aims. Acknowledges importance of providing age appropriate interview guides.<br>Clear explanation of how interview guide questions developed from scoping review and consultation with service users. |

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|  |  |  | Sense of relief, get back to normal, and miss safety of hospital.<br>***Co-ordinating transition and ongoing care***<br>Continued access to healthcare professionals was important. Felt reassured.<br>***Problem-solving.***<br>When felt abandoned by healthcare services – difficulty accessing services and equipment, advocating for child.<br><br>**<u>Key findings</u>** :<br>Injury described as a major event which disrupted lives.<br>Mixture of impacts evident immediately after injury and some developing later.<br>Restriction and resumption of activities & reliance on parent was a major issue for young people.<br>Many parents and children reported PTSD symptoms emerged after hospital discharge.<br>Importance of community to support recovery and resilience.<br>Experiences of participants focused on psychosocial factors (despite type or nature of injury). | Researcher acknowledges their experience in the field as that they were fully trained in interviewing children and worked closely with children who had experienced traumatic injury.<br><br>Information provided regarding ethical approval.<br><br>Consent and assent gained. Participants could choose how and where they took part due to sensitivity of topic.<br><br>Description of data analysis process and how themes were derived from the interview topics or data; some data quotes included in results to demonstrate themes. Data saturation reached.<br>The researcher involved multiple peers in data analysis. |

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| | | | **Implications for medical professionals :**<br>Suggests there should be multidisciplinary ‘one-stop shop’ for post discharge care.<br>Suggests more support needed to support resilience by engaging in play after injury to maintain friendships.<br>Should be screening of both psychological and physical health long term.<br>Parent mental health important to support children. | Findings are explicit and discussed in relation to the research aims and context.<br><br>Discussion of contribution of the research to the field with implications for practice clearly explained. |
| Jones, S., Tyson, S., Davis, N., & Yorke, J. (2020). Qualitative study of the needs of injured children and their families after a child’s traumatic injury. *BMJ Open*, *10*(11), e036682. ENGLAND | To explore the needs of children and their families after a child’s traumatic injury.<br><br>Participants<br>Children (n=13) and their parents (n=14). 5 additional parents (of children who did not take part). Mothers n=18) Fathers (n=1) Guardian (n=1). | Qualitative.<br>Semi-structured interviews took place between 1-12.5 months after discharge, avg. 8.5). 26 interviews with 32 participants.<br><br>Data analysed through thematic analysis.<br><br>Parent and child data analysed together. | **Themes & Sub themes:**<br><br>**Education and training needs**:<br>**Education***:* needed education about injury and recover, symptoms, support and why they occurred.<br>**Training:** wanted training in preparation for hospital discharge – coping strategies, care treatment and opportunities to practice.<br><br>**Information needs**:<br>**Effective communication and information sharing :**<br>Participants wanted clear sufficient timely information to understand what was happening. Varied desire | The aim of the research was clear and well positioned in the wider context with a focus on the impact of childhood injury on the child and their family after discharge due to an identified gap.<br><br>Research addresses why the qualitative design suits the research. Acknowledge that qualitative self-identified needs are subjective, but provide insight into participants lived experiences. |

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| | Criteria: Child discharged over 2 weeks ago, but within 12 months. Included all types of injury with injury score >8,<br>Age: 5-16 years old.<br>No ethnicity or demographic data. | Themes coded for in analysis initially emerged from interview questions topic areas (experiences of health and community services after discharge and the social, emotional physical and practical impact of the injury) which were based on a previous scoping review of the literature.<br>No theoretical underpinnings identified. | for information – valued access to and clear explanations from professionals and up to date information. Identified issues regarding administration, multiple professionals, conflicting information and medical jargon.<br>**<u>Service needs</u>:**<br>**Accessible and timely services:** services near home preferred, issues with administration, access to services for the family in addition to the child, desire for psychological support in community. Timing was an issue.<br>**Ongoing treatment:** discrepancy between hospital and community psychological care, access to physical care and appropriate rehabilitation goals.<br>**Coordination of care:** challenge of coordinating care post discharge, wished for more help with referrals and appointments. Participants valued having a named contact to vibe involved through hospital, discharge and ongoing care as new problems often emerged once home. Participants valued | Clear discussions of recruitment and purposeful sampling to cover a range of injury and childhood ages to represent real life admissions to trauma hospitals. Does not provide justification for why they did not include children under 6 or parents of infants under 2 at time of injury.<br>Clear explanation of how participants were recruited through two major trauma centres in England via post – or in person following discharge from hospital.<br>Clear description of how the data was collected via semi-structured interviews and why this approach enabled researchers to address research aims. Acknowledges importance of providing age appropriate interview guides.<br>Clear explanation of how interview guide questions |

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|  |  |  | signposting and multidisciplinary care.<br>**<u>Positive partnerships between children families and professionals.</u>**<br>Participants wanted supported positive and trusting relationships – helped to boost morale and sense of hope and offer emotional containment.<br>Need to trust the professionals skills and competence. This helped with encouraging children to adhere to treatment plan despite disliking it.<br>**Additional findings**<br>Post code lottery related to rehabilitation services available.<br>Access to services was a common unmet need in the community setting post discharge.<br>Participants described their unique experiences – however the needs were similar across sample.<br>Participants wanted to be heard and involved in decisions.<br>**Implications**<br>Support needs to be available post discharge as many families did not access services whilst in hospital, | developed from scoping review and consultation with service users.<br>Researcher acknowledges their experience in the field as that they were fully trained in interviewing children and worked closely with children who had experienced traumatic injury.<br>Information provided regarding ethical approval.<br>Participants could choose how and where they took part due to sensitivity of topic.<br>Description of data analysis process and how themes were derived from the interview topics or data; some data quotes included in results to demonstrate themes. Data saturation reached.<br>The researcher involved multiple peers in data analysis. |

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|  |  |  | as their mental health was not an evident issue at the time.<br>Need for single point of contact. Need for screening system for problems after discharge. | Findings are explicit and discussed in relation to the research aims and context.<br>Discussion of contribution of the research to the field with implications for First study they know of to examine needs through recovery for a broad range of injured and ages involving both child and parent perspectives. |
| Jones, S., Tyson, S., Davis, N., & Yorke, J. (2022). Educational support needs of injured children and their families: A qualitative study. *Journal of Rehabilitation Medicine*, *54*, jrm00246. | To explore the educational support needs of children and their families after a child's traumatic injury.<br><u>Participants</u><br>Children (n=13) and their parents (n=14). 5 additional parents (of children who did not take part). | <u>Qualitative.</u><br>Semi-structured interviews took place between 1-12.5 months after discharge, avg. 8.5). 26 interviews with 32 participants.<br>Data analysed through deductive semantic analysis. | **<u>Themes:</u>**<br>**<u>Communication and Information needs</u>**<br>**Access to education needs**<u>:</u> continued educational needs during time off, securing a place at school during time off, school transport needs.<br>**Learning support needs:** flexible approaches to learning/ examinations, need for help to catch up, additional / intensive educational support. | The aim of the research was clear and well positioned in the wider context with a focus on educational support needs of injured children and their family due to limited research in this area.<br>Research addresses why the qualitative design suits the research.<br>Clear discussions of recruitment and purposeful sampling to cover a range |

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| | Mothers n=18)<br>Fathers (n=1)<br>Guardian (n=1).<br>Criteria: Child discharged over 2 weeks ago, but within 12 months. Included all types of injury with injury score >8,<br>Age: 5-16 years old.<br>No ethnicity or demographic data. | Themes coded for in analysis the data.<br>Parent and child data analysed together.<br>No theoretical underpinnings identified. | **Environmental adaption and social integration needs** *:* often physically isolated from peers, adaptions to maintain safety, friendship issues, friendships a protective factor, participation needs.<br>**Educational support needs:**<br>**Understanding the injury:** schools limited knowledge about injury management, apprehension about a child's return to school and participation in the curriculum.<br>**Coordination and information exchange***:* challenges of information exchange, key worker role (co-ordination, advice, facilitate information exchange).<br>**Key points**<br>Profound impact on their education.<br>Parents often sharing information with school.<br>Return to school reliant on parent proactive involvement.<br>All parties apprehensive about school return but were receptive to advice. | of injury and childhood ages to represent real life admissions to trauma hospitals.<br>Clear explanation of how participants were recruited through two major trauma centres in England via post – or in person following discharge from hospital.<br>Clear description of how the data was collected via semi-structured interviews and why this approach enabled researchers to address research aims.<br>Acknowledges importance of providing age appropriate interview guides.<br>Clear explanation of how interview guide questions developed from scoping review and consultation with service users.<br>Researcher acknowledges their experience in the field as that they were fully |

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|  |  |  | Changed physical and cognitive abilities.<br>Several children found it hard to relate to peers after the incident and found it hard to start new school.<br>Isolation was exacerbated as they were often separated because of behaviour or physicality.<br>Returning to school was a positive milestone in their recovery but parents were anxious.<br>Need support to return to school but to continue education home before returning.<br><br>Changes needed were often very simple and accessible.<br><br>Those with most profound needs – more structured support than those just needing to catch up.<br><br>**Implications :**<br>Collaborative working to amend policies to cover full scope of disabled children's needs. Need a central key worker to navigate and coordinate health and education.<br>Education statutory policy – to provide suitable education – difficulties around sudden onset and | trained in interviewing children and worked closely with children who had experienced traumatic injury.<br><br>Information provided regarding ethical approval. Consent and assent gained. Patient information sheets, consent and assent forms reviewed by professionals. Participants could choose how and where they took part due to sensitivity of topic.<br><br>Parents were able to provide insightful prompts for children. Mostly mothers.<br><br>Explains why parent and child data analysed together as parents testimony was mostly about their children and because their needs are linked.<br><br>Description of data analysis process and how themes were derived from the interview topics or data; |

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| | | | schools lack knowledge about injured children. | some data quotes included in results to demonstrate themes. Data saturation reached.<br>The researcher involved multiple peers in data analysis.<br>Findings are explicit and discussed in relation to the research aims and context.<br>Discussion of contribution of the research to the field with implications for First study they know of to examine needs through recovery for a broad range of injured and ages involving both child and parent perspectives. |
| Foster, K., Van, C., McCloughen, A., Mitchell, R., Young, A., & Curtis, K. (2020). Parent perspectives and psychosocial needs 2 years | To explore parent experiences two years following their child's critical injury.<br><u>Participants:</u> Child must have been 0-12 years old, injury severity | Interpretive qualitative design.<br>Telephone interviews 2 years post injury.<br>Semi-structured interview guide covering: Child | **<u>Themes:</u>**<br>**<u>Recovering from child injury.</u>**<br>Physical and emotional & are linked closely together: emotional recovery reliant on physical recovery. Parents described their child and family as returning to normal or being back on track. | The aim of the research is clear and positioned in the wider context with a focus on the psychosocial impact of childhood injury on the family.<br>Qualitative appropriate as research aim is to explore the subjective and personal |

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| following child critical injury: A qualitative inquiry. *Injury*, *51*(5), 1203–1209.<br>Australia. | score >16 and / or ICU admission.<br>22 parents of 18 children took part (mother n=12, father n=10).<br>Child mean age =8.<br>Most participants were partnered or married (89.5%) with more two or more children (84.2%) | recovery, Needs, Impact and resilience.<br>Thematic analysis. Inductive approach.<br>No theoretical underpinnings identified. | 1/3 children had ongoing functional and / or emotional needs.<br>**Managing the emotional impact of injury.**<br>Parents and child's mental health very linked, parents experiences and needs closely related to their child's recovery and support available to them.<br>2 years on, most parents had emotionally recovered from the experience and felt positive about the future and lucky their child had survived.<br>Some parents overprotective and sense of loss for their child's future and a sense of distress and helplessness if child recovery slow and ongoing.<br>**Being resilient and finding ways to adapt.**<br>Resilience was defined in different ways but generally focused on being strong in face of adversity. Parents did not always find it easy.<br>**Strategies and resources:**<br>**Parents :** being flexible, determined and having positive mindset and being grateful. Parents drew on | experiences of the participants.<br>, clear explanation of participant criteria and purposeful sampling to cover a range of injury and ages but not why that age only or why that severity score?<br>No details of how participants were recruited specifically.<br>, clear description of how the data was collected and why this approach enabled researchers to address research aims.<br>Used telephone interview method.<br>. No explanation of how interview guide questions emerged except for in relation to research questions.<br>no consideration of role of researchers and potential bias. |

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| | | | their own resilience, or shifted their perspective due to their child’s injury.<br>Meaning making of adverse events.<br>**Family and friends**: Having strong relationships, talking openly with friends.<br>Health care and community: seeking psychological support, seeking health with everyday tasks, flexible working arrangements.<br><br>**Key findings**<br>16/22 children - fully recovered physically, 13/22 fully recovered emotionally.<br>18/22 parents – fully or mostly recovered emotionally.<br>4/22 parents – negative emotions due to child’s recovery being slow.<br><br>Focus on returning to the life pre-injury – return to ‘normal ‘and to their routine.<br>Aspiration and outlook on life changed, as had expectations for their child. More protective.<br>If parents involved in accident, more PTSD.<br>Importance of accessing support where available. | Involved multiple researchers in data analysis.<br><br>Can’t tell– not clear how ethical issues were considered. Information provided regarding ethical approval.<br><br>clear description of data analysis process and how themes were inductively taken from the data in relation to research questions; quotes included in results to demonstrate themes.<br><br>Acknowledges findings are explicit and discussed in relation to research aims.<br><br>Discussion of contribution of research, and implications for practice. |

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| | | | Limited psychological / emotional support offered by health professionals – mostly from family and friends.<br>**<u>Implications :</u>** parenting support post injury to prevent adverse outcomes for family, their dynamic and child development. | |
| Foster, K., Mitchell, R., Young, A., Van, C., & Curtis, K. (2019). Parent experiences and psychosocial support needs 6 months following paediatric critical injury: A qualitative study. *Injury*, *50*(5), 1082–1088. Rzh<br>Australia. | To explore parent experiences and psychosocial support needs in the 6 months following child critical injury.<br>Child must have been 0-12 years old, injury severity score >16 and / or ICU admission.<br>30 parents of 23 children took part. Mothers (n= 18) Father (n=12).<br>Child mean age = 7.5 years. | <u>Interpretive qualitative design.</u> Phone interviews.<br>Semi structured interviews using guide to cover : parent experiences in the size months following their child's injury, parents ad family's main needs during this time, and how these needs were / not met and by whom. | Parents report that child's psychological wellbeing was the most challenging aspects.<br>**<u>main themes</u>** <u>:</u><br>**<u>integrating back into home life</u>**<br>Initial focus on physical recovery- then emotional. Focus on returning to normal and difficulties around this due to ongoing issues. Issues with attending medical follow up appointments and transitioning back to school. Most children had negative emotional reactions related to injury event and the impairments. Parents needed to adapt their parenting style to support children's behavioural problems (2/3 of children). | the aim of the research is clear and positioned in the wider context with a focus on the psychosocial impact of childhood injury on the family.<br>Qualitative appropriate as research aim is to explore the subjective and personal experiences of the participants.<br>research addresses why the qualitative design suits the research.<br>Clear explanation of participant criteria and purposeful sampling to cover a range of injury and ages but not why that age |

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|  | 2/3 of children injured in traffic accident. | Thematic analysis. Inductive approach.<br>No theoretical underpinnings identified. | **Adjusting mentally and emotionally to injury**<br>Parents significantly influenced by : physical and emotional recovery patterns of their child. Parents often neglected their own mental health.<br>**Coping with injury as a family**<br>Parents happy to come home.<br>Older child parent dyads – found their relationships had strengthen, for younger children – har to determine the impact of the injury on relationship.<br>Family dynamic changed and all family impacted.<br>Difficulties reintegrating into previous life and community.<br>Reiterating importance of parent and families psychosocial wellbeing to maintain child wellbeing.<br>**Navigating resources to meet family needs.**<br>Limited direct contact or follow up support. Little offer of psychosocial support for children. When returning for check-ups – relationship with staff still important. Reliance on professionals for information, not always provided and not always a | only. No details of how participants were recruited specifically.<br>clear description of how the data was collected and why this approach enabled researchers to address research aims. No explanation of how interview guide questions emerged except they relate direct to research question.<br>no consideration of role of researchers and potential bias. Involved multiple researchers in data analysis<br>provide information regarding ethical approval and consent; all participants were offered follow up psychosocial support information.<br>clear description of data analysis process and how themes were derived from the data; some data quotes included in results to demonstrate themes. |

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| | | | single point of contact. Post code lottery for services.<br>**Child factors :** injury related, psychological / emotional.<br>**Parent factors :** psychological / emotional – self, psychological / emotional – child, social.<br>**Family factors :** psychological / emotional – self, psychological / emotional – others and child, social**.**<br>**Social, environmental and community factors :** social, community resources, structural support.<br>**Implications:** family centred practice is key, need for more psychosocial support post discharge, anticipatory guidance about what to expect when home. | findings are explicit and discussed in relation to research aims<br>Discussion of contribution of research and how it has had a direct impact on hospital support. Discussion of implications for practice.<br>Acknowledges that sample is a group of English speaking parents. |
| Atkins, E., Colville, G., & John, M. (2012). A 'biopsychosocial' model for | To investigate how families understand their recovery following a PICU admission. | Qualitative, grounded theory. Semi-structured interviews with interview prompt. | **Developed biopsychosocial model of recovery.**<br>**Bio;** focus on physical recovery at first. Not well when first left hospital which was a surprise to participants. | The aim of the research is clear and positioned in the wider context with a focus models of recovery and the psychosocial impact of a PICU admission. |

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| recovery: A grounded theory study of families' journeys after a Paediatric Intensive Care Admission. *Intensive & Critical Care Nursing*, *28*(3), 133–140.<br>ENGLAND.<br>UK. | 44 families invited to take part, 8 did.<br>Children, aged 5-17 (n=5), father (n=5) mothers (n=8).<br>7 families white British, 1 family Asian British. | 8-18 months after PICU admission.<br>Used comic strip for children, play figures for younger children, sticker and emotions to explore their experiences.<br>Underpinned by Engel's (1977) biopsychosocial model but this research adapts and builds upon it. | Physical impact on parents too trough no sleep and poor nutrition. Physical health as a barrier to other aspects of recovery.<br>**Psycho;** once physical health improved, they recognise the enormous emotional toll. People were striving for normality. Burden on family, Importance of telling stories and creating a narrative.<br>**Social:** physical health impacts on social re-integration. PICU had impact on social identity, different to pre-PICU. Roles of children and parents changed following PICU.<br>**Working towards a new normal** Normality was a reoccurring theme in all three areas of the model. Changed them and their recovery journey is different to before.<br>**Roadblocks to recovery:**<br>**Pathologising recovery:** not talking about it neglected psychological and socio-emotional aspects of recovery. Societal expectations played a role in regards to views of recovery. | Qualitative and grounded theory appropriate to be person centred and driven by the participants' experience. Appropriate for aims of research.<br>Researcher addresses why the design suits the research – interviews and provided child friendly resources to accommodate children under 12.<br>Clear discussion of recruitment methods and participation selection. Acknowledge that parents self-selected to participate and so parents who did not choose to take part may be having a different experience.<br>Chose to involve parents and children although do not distinguish between the two groups in findings except for in quotes. Their data was analysed together. |

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| | | | **Medicalisation of recovery:** confusing messages from staff. Focus still on physical recovery.<br>**Implications for medical practice**: families should be advised what they can expect following discharge, once child is stable. Post discharge clinics. | Clear description of how the data was collected and why this approach enabled researchers to address research aims. Data was collected to test out new themes as the model emerged and participants validated the findings.<br>Considered relationship between researcher and participants by involving parents and children throughout process to ensure interpretation was correct.<br>Researchers acknowledge complexity of work In this field. Ethical approval received. Involved children and parents in designing methodology to ensure appropriate.<br>Description of data analysis process and how codes were derived from the data; some data quotes included in results to demonstrate themes. Involved all three |

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| | | | | authors in data analysis to improve inter-rater reliability. Gathered data until data saturation was reached.<br>Findings are explicit and discussed in relation to aims and implications discussed. |
| Atkins, E., Colville, G., & John, M. (2020) Families' Experiences of Life in the Year after a Child's Critical Illness: Navigating the Road to a "New Normal".<br>UK. | To describe families' experiences over the first year post discharge. To investigate what strategies and processes the how families (parents and young people) found helpful.<br>44 families invited to take part, 8 did.<br>Children, aged 5-17 (n=5), father (n=5) mothers (n=8). | Qualitative, grounded theory. Semi-structured interviews with interview prompt. 8-18 months after PICU admission.<br>Used comic strip for children, play figures for younger children, sticker and emotions to explore their experiences.<br>No theoretical underpinnings identified. | **Themes:**<br>**Just getting through** – ways of managing early period of recovery. Parents did not have time to think whilst in hospital which changed when they got home. When discharged, need to reintegrate into wider network. Strategies involved: throwing themselves into work, keeping busy, detaching and thinking positively.<br>**A changed person** – challenge of how they viewed themselves, parents more protective.<br>**Striving for normality-** process took longer than expected and was frustrating, life was not the same.<br>**Positive growth experiences during recovery** – shift from just copping to recovering. Participants | The aim of the research is clear and positioned in the wider context with a focus on models of recovery and the psychosocial impact of a PICU admission.<br>Qualitative because research aim is to explore the personal experiences of the participants to develop an understanding of the recovery process.<br>Researcher addresses why the design suits the research – interviews and provided child friendly resources to accommodate children under 12. |

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|  | 7 families white British, 1 family Asian British. |  | could look back and realise what has happened and have a new perspective on life.<br>.<br>**<u>Developing a narrative</u>. -** Process what has happened, need to tell their story, ongoing process involving re-authoring story over time. Barriers to telling story include fear of upsetting others and incomplete memories.<br>**<u>Key findings</u>**<br>All participants need to talk in depth about their experience of the PICU admission and identified as key to their reflections on recovery.<br>Developed a model pathway from admission to the new normal.<br>Psychosocial adaptions begin after child has largely recovered<br>**<u>Implications:</u>** created a leaflet to highlight the roadmap to recovery for families.<br>Support for diaries in hospital to support understanding and creation of stories. | Clear discussion of recruitment methods and participation selection.<br>Chose to involve parents and children although do not distinguish between the two groups in findings except for in quotes. Their data was analysed together.<br>Clear description of how the data was collected and why this approach enabled researchers to address research aims. Data was collected to test out new themes as the model emerged and participants validated the findings.<br>Considered relationship between researcher and participants by involving parents and children throughout process to ensure interpretation was correct.<br>Researchers acknowledge complexity of work In this field. Ethical approval |

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|  |  |  |  | received. Involved children and parents in designing methodology to ensure appropriate.<br>Description of data analysis process and how codes were derived from the data; some data quotes included in results to demonstrate themes. Involved all three authors and an independent rater in data analysis to improve inter-rater reliability. Gathered data until data saturation was reached.<br>Findings are explicit and discussed in relation to aims and implications discussed. |
| Manning, J. C., Hemingway, P., & Redsell, S. A. (2017). Stories of survival: Children's narratives of psychosocial | To explore long term-psychosocial wellbeing of childhood survivors of critical illness through their stories. | Qualitative exploratory using in-depth interviews and art based methods (photo, drawing).<br>Narrative Psychological Analysis of the | <u>**Themes :**</u><br>**disruptive lives and stories;**<br>Confusion, doubts and absence of memory related to PICU admission. Confusion if story did not align to someone else's. However other people's stories also helped them to rebuild their own.<br>Focus on past, present and future in their stories. | , the aim of the research was clear and positioned in the wider context with a focus on the psychosocial impact of an admission to PICU.<br>The research addresses why the qualitative design suits the research as aim is |

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| well-being following paediatric critical illness or injury. *Journal of Child Health Care*, *21*(3), 236–252.<br>UK. | 9 children took part (aged 6-15, 6 boys, 3 girls).<br>Purposeful sampling through retrospective screening of a PICU admission base. | data – holistic content analytical approach.<br>Data collected 6-20 months post discharge, 3 interviews over 6 months).<br>Drew on child-centred approach viewing children as knowledgeable, interactive and social beings who can autonomously make decisions about involvement, methods and conduct of the inquiry. | **exposure to death and dying;**<br>Survivors became aware of their own mortality. They tried to navigate this through reflection, dissociation and sense making.<br>Reflecting on this caused anxiety, especially when diagnosed with a chronic health condition due to critical illness.<br>**<u>Dealing with different social worlds and identities</u>**<br>Experience was a challenge to their identity.<br>Identity redefined during the stories.<br>- Focused on their growth, exposure to new life and events, recovery and residual disability.<br>- Restrictions and experiencing protection by others.<br>- Social stigma – experienced by older participants.<br>- Not always disclosing or talking about it to prevent upsetting others.<br>1. **getting on with life.**<br>-focus on present and future tenses. | to explore the subjective and personal experiences of the participants.<br>clear discussions of recruitment and participant selection. Acknowledge they do not know why other participants did not want to take part and this is a limitation. Demographic data obtained<br>clear description of how the data was collected and why this approach enabled researchers to address research aims. Clear explanation of how and why activities were used to collect data.<br>Researcher acknowledges their experience and role in interviewing participants over a long period of time. Reflective notes kept regarding performative and relational reflexivity.<br>information provided regarding ethical approval. |

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| | | | Desire to return to their prior 'able' selves.<br>Resilience and positive emotions and enhanced wellbeing.<br>Return to school helped to stop thinking about death – preoccupied (importance of normalcy).<br><br>**Key points:**<br>The stories of survival do not fit into any of the conceptualised trajectories of survival that exist – they are chaotic, messy and complex.<br>Confusion and uncertainty appear there up to at least 20months post PICU.<br>Narrative – hope emerged – telling a story to free themselves. | Consent and assent gained. Participants debriefed and signposted accordingly and anonymity discussed.<br><br>clear description of data analysis process and consideration of credibility, dependability and trustworthiness of study. Evidence of narrative psychological analysis process. Some data quotes included in results to demonstrate themes.<br><br>findings are explicit and discussed in relation to research aims and context.<br><br>Unique contribution to the research field especially as involved children activiely in designing and collecting the data. , discussed implications for practice. |
| Williams, C. N., Eriksson, C., Piantino, J., Hall, T., Moyer, D., Kirby, A., & | To determine outcomes important to the patients and their families and engage families in | Participants offered financial incentive.<br>Qualitative – focus groups. | **Themes :**<br>**<u>PNCC is an intense emotional experience for the whole family</u>**<br>(acute & chronic emotions, source of support, effects of emotional | the aim of the research is clear and positioned in the wider context with a focus on the impact of paediatric neuro-critical care. |

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| McEvoy, C. (2018). Long-term Sequelae of Pediatric Neurocritical Care: The Parent Perspective. *Journal of Pediatric Intensive Care*, *7*(4), 173–181.<br>USA. | identifying barriers to care and potential interventions to improve outcomes.<br>Parents of PNCC survivors (0-19 years old at admission) identified through medical records. Must have had critical care intervention during admission.<br>Parents mailed and contacted via phone.<br>36 contacted, 16 took part (unclear demographics, mostly female).<br>Between 1-8 years post discharge. | 4 groups of 4.<br>Thematic network analysis used on transcripts of focus groups.<br>Used interview script framework to guide themes.<br>No theoretical underpinnings identified. | responses, barriers and interventions).<br>- Parents experienced acute stress and anger during hospital, and lashed out at others. Fear of the unknown and loss of control caused stress. Grief and guilt pertains years afterwards.<br>- Impacted on siblings and family relationships.<br>**PNCC survivorship is a chronic illness** (physical, emotional, psychological and cognitive sequelae, ongoing medical needs, barriers to care, interventions)<br>- Children had cognitive and physical issues, difficulties with going to school or social impairments.<br>**PNCC has a significant psychological and social impact** (psychological, financial and social distress, barriers and interventions).<br>- Parents mostly discussed the psychological and emotional impact on the family as a whole, more so than the physical sequelae. | Qualitative appropriate as research aim is to explore the subjective and personal experiences of the participants.<br>Researcher does not address why they chose focus group over interviews.<br>Clear discussions of recruitment and participants. Demographic data obtained (although unclear), clear information provided about why some parents did not take part. (because of not interested English or not available during schedules groups).<br>Clear and explicit description of how data was collected.<br>Description of data analysis process and how themes were derived from the interview topics or data; |

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|  |  |  | - 9 participants' escribed a diagnosis of PTD, depression or anxiety.<br>- Described children as fearful and anxious.<br>Postcode lottery for access to service.<br>**<u>Implications:</u>** lack of awareness from staff, develops and evaluate interventions around PICS-P. Parents would like to have more acknowledgement of the psychological impact through support services (e.g. acknowledgment of early onset symptoms, psychological support, support groups and educational materials in layman terms). | some data quotes included in results to demonstrate themes.<br>Can't tell if relationship between researcher and participants adequately considered. The researchers were trained and used structured questions to minimise bias, but unsure where questions came from, unsure if multiple researchers analysed data.<br>information provided regarding ethical approval and anonymity discussed. Consent gained.<br>findings are explicit and discussed in relation to research aims and context.<br>Discussion of contribution of research in the field; as well as implications for practice. |
| Egberts, M. R., Geenen, R., de Jong, | To qualitatively examine the way in which children | Qualitative. | **<u>Themes</u>** | aim of the research was clear and positioned in the wider context with a focus |

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| A. E., Hofland, H. W., & Van Loey, N. E. (2020). The aftermath of burn injury from the child's perspective: A qualitative study. *Journal of Health Psychology*, *25*(13/14), 2464–2474. a9h.<br><br>Netherlands. | recall the burn injury event. How they reflect on the hospitalization period and how they cope with their injury.<br><br>Children aged between 12-18 years old, at least 3 months post discharge.<br><br>Researcher contacted parents by telephone or at check up contact.<br><br>4 girls, 4 boys (14.85 avg years olds). | Semi-structured interviews 4-17 months after discharge (avg 7)<br><br>No theoretical underpinnings identified. | **Vivid memories**: *experiencing the accident; look of wounds; pain*; *positive hospital memories.*<br><br>**Importance of parental support :**<br>Important both at hospital and after discharge; awareness of parents distress due to wounds; needing a break; thankful for parents; able to talk about injury in aftermath.<br><br>**Psychosocial impact and coping**: concern it might happen again, reaction of others, coping.<br>To cope: processing trauma by talking and looking at photos, facing their fears, put things into perspective and focusing on positive outcomes. Avoiding places or objects was reported by some children.<br><br>**Key points**<br>Idea of normalcy and desire to return to normal.<br>Anxiety it might happen again – scared and anxious.<br>Narratives to process the trauma – talk it through.<br>Perspective change – resilience.<br>Focused positive outcomes such as survival. | on the impact of childhood burns.<br><br>Qualitative appropriate as research aim is to explore the subjective and personal experiences of the participants.<br><br>Purposeful sampling to ensure variation in characteristics; research explains how participants were selected and recruited.<br><br>Clear and explicit description of how data was collected, no explanation of interview schedule questions, however they were reviewed throughout research based on information obtained within previous interviews – so not completely individually led.<br><br>Researcher acknowledges importance of rapport with participants but not clear whether there was more consideration of the relationship. Interviewers |

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| | | | Implications for care provided based on findings and previous literature – related to the paediatric medical trauma stress integrative model. | were trained psychology students.<br>Researcher acknowledges sensitivity of topic and ensured participants consented and were signposted to support accordingly.<br>Clear description of data analysis process, multiple authors reviewed data, data saturation was reached.<br>Clear findings and discussed in relation to research aims and context.<br>Unique contribution to the research field, discussed implications for practice and future research. Acknowledges that findings only apply to children aged 12 and over so important to consider the experiences of young children who may have a different experience due to language and cognitive capacity. |

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| Wray, J., Brown, K., Tregay, J., Crowe, S., Knowles, R., Bull, K., & Gibson, F. (2018). Parents' experiences of caring for their child at the time of discharge after cardiac surgery and during the post discharge period: Qualitative study using an online forum. *Journal of Medical Internet Research*, *20*(5). | To elicit parental experiences of caring for a child with CHD after discharge following cardiac surgery | 73 parents of children with heart diseases took part in the forum and answered questions.<br>19 questions posted. Mixed response – ranging from 14-43 participants responding to each one.<br>No theoretical underpinnings identified. | One qualitative part of a wider project reviewing provision of care for children with congenital heart disease after surgery during discharge period.<br>**<u>Isolation was the main theme.</u>**<br><u>Physical</u> (due to own anxieties or concerns around infection)<br><u>social</u> (interactions with others, not able to be "normal" parents).<br>**<u>Knowledge.</u>**<br>Not enough information given.<br>**<u>Psychological and emotional impact</u>**<br>Anxiety, developed into symptoms of PTSS. Unprepared for the experiences they were having – challenge of feeling relieved but scared. Some experienced a fog or confusion. Felt unsupported and worried. Role of the parent changed.<br>**<u>Challenges</u>**<br>Practical issues – postcode lotter, receiving information in hospital | Clear aim in wider context of research. Qualitative appropriate to explore personal experiences, however interviews would have been better.<br>Research addresses barriers to research and they are using an online forum to overcome this.<br>Sampling strategy appropriate for aims of research, however unable to collect any demographic data about children.<br>Clear description of how data was collected and analysed.<br>Acknowledged the use of bias in using a forum to ask questions and interpretation was based solely on what they replied. |

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| UK. | | | then nothing about discharge, getting medicine, feeding.<br>**Mitigating factors**<br>Access to training or information before going home, specific signs to look out for, open and ongoing support from local hospital, positive relationships with staff.<br>Support network. | Ethical approval was obtained and addressed issues of data collection method. Support links provided.<br>Data analysis and coding was clear. Multiple researchers reviewed data.<br>Clear statement of findings. Discussion of contribution to research field. |
| Lerret, S. M., Johnson, N. L., & Haglund, K. A. (2017). Parents' perspectives on caring for children after solid organ transplant. *Journal for Specialists in Pediatric Nursing*, *22*(3), n/a-N.PAG. a9h.<br>USA. | Explore parents' perspectives on the discharge transition from acute hospitalisation following SOT.<br>Parents or guardians of child with organ transplant.<br>42 parents completed all 3 interviews (female n=41, male n=1) across 5 hospitals | data.<br>Received a gift card.<br>Qualitative component of a larger mixed methods longitudinal study.<br>3 interviews – 3 weeks, 3 and 6 months post discharge via telephone.<br>Transitions Theory (Meleis et al, | **Themes :**<br>**getting back to normal**:<br>Most prominent at 3 weeks post discharge.<br>Biggest challenge was establishing a new routine (3 weeks) due to ongoing medication, treatment and appointments.<br>Parents juggling multiple responsibilities and roles including other children.<br>Parents struggling with their own needs both emotionally and physically.<br>**becoming routine**:<br>At the 3 month time point, they had established a routine. | aim of research is clear and positioned in wider context with a focus on post hospital care.<br>Qualitative appropriate because research aims to explore the subjective and personal experience of participants.<br>convenience sample used, clear discussion of participant selection. Unclear why not all eligible parents took part.<br>clear description of how data was collected. |

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| | Child average age 2.8 years (range 3 weeks to 17.5 years).<br>Demographic | 2000) provides an organising framework for transition from hospital to home for chronic illness care.<br>Theory stipulates there are four main components of transition : nature of transition, transition conditions, nursing therapeutics and patterns of response | Illness before the transplant was worse and so this was a relief in comparison.<br>Regaining health and function as a challenge for many parents – addressing delays and new behaviours.<br>**facing a future.**<br>At 6 months post discharge, parents were looking forward.<br>Parents changed by their experiences.<br>Many parents were vigilant and worried about child becoming unwell again, attributing all symptoms to the transplant<br>Children were shifting to community care, parents lost connection with organ team which was difficult due to concerns around lack of knowledge.<br>Parents felt they knew more than professionals.<br>**Key implications for practice**<br>Staff should consider changing needs for child and wider family, particularly as they transition to community care. | Unsure of where interview schedule topics came from or what questions were asked. Unclear whether different questions asked at different interview points (3, weeks, 3, months and 6 month).<br>no clear consideration of role of researcher and potential bias.<br>Research provides information regarding ethical approval.<br>lear description of data analysis and how data was coded. Multiple researchers reviewed data.<br>clear statement of findings discussed in relation to the research aims. Makes reference to theory underpinning research in the discussion, but not in much detail. |

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| | | | | Unique contribution in relation to the experience of families after child organ transplant. Implications for practice discussed. |
| McKevitt, C., Topor, M., Panton, A., Mallick, A. A., Ganesan, V., Wraige, E., & Gordon, A. (2019). Seeking normality: Parents' experiences of childhood stroke. *Child: Care, Health & Development*, *45*(1), 89–95. a9h.<br>UK. | To document the experiences of families of childhood stroke survivors from their perspective.<br>12 parents of children with stroke.<br>5 had no or mild neurological deficit and 7 had moderate to severe deficit as determined by the Recovery and recurrence Questionnaire across 5 domains of function: left / right sensorimotor, expressive and receptive language and | Tried to recruit young people, only 2, not included their data.<br>Qualitative semi structured interviews.<br>Face to face or via telephone.<br>Thematic analysis used.<br>No theoretical underpinnings identified. | **Themes.**<br>**<u>Stroke impacted on child.</u>**<br>11/12 reported physical consequences and/or functional impact.<br>Many children had psychological and emotional problems.<br>Some children had cognitive issues (e.g. slow processing).<br>Impacted on their social life, others perception (social stigma), take part in activities.<br>**<u>Impact on family.</u>**<br>Shocking and stressful, sleepless nights, clinical depression. Family relationships strained. Small group of parents felt guilty due to concerns around genetics or something they did or did not do.<br>Time out of work.<br>**<u>Participants view of quality of clinical care.</u>** | There was a clear aim positioned in the wider context.<br>Qualitative appropriate because research aims to explore the subjective and personal experience of participants.<br>Recruitment is unclear. Participants came from participating in a previous survey, discussion of criteria but do not provide details. No demographic data obtained.<br>Topic guide reviewed by participants but no examples of questions provided.<br>Clear data collection and analysis. |

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| | cognition / behaviour.<br>Children ranged from neonate to 15 years 5 months.<br>Time since stroke – within a year to 5 years. | | Frustration with admission to hospital if professionals reluctant to refer to specialist services.<br>Happy with acute inpatient care.<br>Insufficient information about home care or what services to access.<br>Lot of complex language around stroke.<br>Post code lottery.<br>Hard to access professional support – child's behaviour and emotional needs. Lack of general psychological support available.<br>**Experiences related to education:**<br>Positive and negative experiences attributed to : risk assessment, staff willing to help find solutions, uncertainty about how to help, cognition, awareness of rare ness of stroke – people not knowing how to manage, needs may become apparent over time. Parents had to advocate and communicate with school staff regularly.<br>**Desire to construct a sense of normality.**<br>Importance of constructing a sense of normality for the child and their family. | Ethical approval obtained.<br>clear statement of findings discussed in relation to the research aim.<br>Discussion of contribution of research in the field; as well as implications for practice. |

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| | | | Wanting to get back to normal or to be normal.<br>Was not straightforward – balance of parent and family roles, information is important in this sense. The information of professionals is important.<br>Sought support from organisations and social networks – families with same experiences.<br><br>Implications for post discharge care – access to information, raised awareness in community care and consideration that their needs will develop and change over time. | |
| Fayed<br>, N., Cameron, S., Fraser, D., Cameron, J. I., Al-Harbi, S., Simpson, R., Wakim, M., Chiu, L., & Choong, K. (2020). PRIORITY OUTCOMES IN CRITICALLY ILL CHILDREN: A | To identify outcomes prioritised by patients and their families following a critical illness and determine overlap between patient-centred and researcher-selected study outcomes.<br><br>21 participants | Qualitative study within a larger prospective study of functional recovery.<br><br>Semi-structured interviews between 3.5 – 12 months post discharge.<br><br>Applied the WHO International classification of functioning, | **<u>Patient centred outcomes</u>**.<br><br>**Survival:** diagnosis important but parents feared prognosis, and fear of death was present during early periods of critical illness.<br><br>**Functional recovery:**<br>- *body function*: prioritized by parents as a first step and the need for rehabilitation was important within and beyond PICU. Parents then wanted children to regain cognitive and emotional function. | Research aim to identify what outcomes are most important to parents during and following illness.<br><br>Qualitative methodology appropriate because research aims to explore the subjective and personal experience of participants.<br><br>Data collected until saturation.<br><br>Used a mixture of deductive and inductive coding driven |

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| PATIENT AND PARENT PERSPECTIVE. *American Journal of Critical Care*, *29*(5), e94–e103. rzh.<br>US A. | Mothers n=19, fathers n=1) 1 young person.<br>Children aged 1.5 – 17.7 years old. Half of sample had pre-existing chronic medical condition.<br>Purposeful sampling to adequately represent general PICU population across a range of characteristics. | disability and health for children and youth (ICF-CY, 2007) framework and the Weecover outcome measures in critical ill children to code the interviews.<br>Codes were grouped into themes and subthemes according to the ICF-CY domains. Inductive coding used if data did not fit into existing codes. | - *Ability to participate in activities*: daily routine across home, social and school contexts.<br>- *Health conditions:* parents were very aware and prioritising their health.<br>**Quality of life:** emotional wellbeing prioritised both during illness and post PICU. Wanted to ensure comfort and minimise suffering. Influenced by life expectation and baseline health.<br>**<u>Family centred outcomes:</u>**<br>**Family psychosocial outcomes:** Parents struggled to cope and had their own physical and emotionally distressing symptoms. Uncertainty of role was hard and balancing demands and responsibilities. Impact of illness on sibling was important.<br>**Family experiences and supports:** During PICU valued organisational support (e.g. parking, accommodation). Post discharge, valued social services, education support and legal services. Valued a supportive and attuned medical team with regular | from the participants data - themes were coded in relation to the ICF-CY domains or from the data if not matched to the domains.<br>purposeful sampling to ensure variation in characteristics; research explains how participants were selected and recruited.<br>Unclear reason why more young people did not take part as it is unclear whether parents and children both present in interviews, mentions that children deferred to their parents or did not take part due to physical or cognitive factors.<br>Used 2 analysts to code the data to improve inter-rater reliability. A member of research team also engaged in analysis.<br>Researchers clearly present patient centred outcomes in contrast to study outcome |

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| | | | communication. Important to feel valued in decision making process.<br>**Relevant ICF-CY Domains**: health condition, body function, activities and participation, environmental factors, health condition.<br>**Implications :** outcome priority changes from admission to post PICU. Outcomes typically measured in medical PICU research do not capture parents' experience. Makes reference to PICS-P and Pics- family as a concept. | measures – however these are determine by parent not child patients.<br>Unique contribution in relation to specific outcome measures used in research area,. |

## Appendix C: Letter of Ethical Approval.

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology
**REVIEWER: Kenneth Gannon**
**SUPERVISOR**: Mary Robinson
**STUDENT: Lucy Stone**
**Course**: Professional Doctorate in Child Psychology
**Title of proposed study**: What are the stories of young children, and their families, who have experienced a hospital admission?
**DECISION OPTIONS:**
**APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
**APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
**NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.
**DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY**
*(Please indicate the decision according to one of the 3 options above)*

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| **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES** |

**Minor amendments required** *(for reviewer)*:
This is a note of advice rather than a required change. The title of the study (which is or will be the registered title) and the title on the information sheets make no reference to the inclusion of teachers in the study. Parents are aware of and consent to their child's teacher being approached, so that is not an issue. However, it is important to note that if there is a decision subsequently to include teachers/staff in the title of the study and thesis then approval for the change will need to be sought in relation to both the registered title and the ethical approval. A second piece of advice is that participants should expressly consent to the thesis being available on ROAR and containing anonymised excerpts of

transcripts and to materials disseminating the research (papers, conference presentations) also containing anonymised excerpts. Furthermore, if the intention is to share a copy of the thesis consent should be obtained to approach participants again in order to do this (though they could be directed to check ROAR as an alternative).
I recommend that the applicant and the DoS discuss these points and decide how to proceed.
**Major amendments required** *(for reviewer):*

N/A

**Confirmation of making the above minor amendments** *(for students)*:

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

Student's name *(Typed name to act as signature):* Lucy Stone
Student number: U1944286

Date: 30.03.2021

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**ASSESSMENT OF RISK TO RESEACHER** *(for reviewer)*
Has an adequate risk assessment been offered in the application form? **YES**
Please request resubmission with an adequate risk assessment
If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

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Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

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MEDIUM (Please approve but with appropriate recommendations)
LOW

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**Reviewer comments in relation to researcher risk (if any).**
N/A
**Reviewer** *(Typed name to act as signature*): Dr Kenneth Gannon
**Date**: 23/03/21
*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

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

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

## Appendix D: Stages of Recruitment

| Phase | Method |
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| 1 | In May 2021, the researcher emailed the poster (see Appendix AF) and parent information letter (see Appendix T) to all of the EPs in their placement Local Authority (LA) and asked them to share this with the SENCo or head teacher at their link primary schools and nurseries. The EPs were also asked whether they knew of any families who met the criteria. The researcher contacted the schools and nurseries they had a direct link with and the local children centres. The researcher followed up with schools in their placement LA on multiple occasions throughout the recruitment period to see if they had identified any potential participants. |
| 2 | In September 2021, the researcher adapted their ethics to allow for wider recruitment (see appendix P). The researcher contacted different professionals within their LA's children services department to aid recruitment. The researcher also shared the research poster and information letter with EPs across the country via email. At this stage, a few schools in the researchers LA did share the research advert with parents via newsletters or put up posters in their schools.<br>Two parents were recruited at this phase. |
| 3 | In October 2021, the researcher adapted their ethics to allow for online recruitment due to challenges in phase 1 and 2 (see Appendix Q). The researcher uploaded the research poster onto Twitter. The researcher also contacted the admins of hospital parent support Facebook groups, to ask whether they would advertise the research poster.<br>Two parents were recruited at this phase. |
| 4. | Once parents made contact, the researcher shared the information letter and consent form via email (see Appendix T) and answered any questions. Once this was signed, they arranged a time to speak at the parent's convenience. The following stages of recruitment did not take |

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| | place until parents provided consent and contact details for the school setting. |
| 5. | If parents consented to the researcher also speaking with their child’s teacher, the researcher then sent an email to the child’s school addressing the head teacher or SENCO and attached a staff member information letter and consent form (see Appendix U) to share with the appropriate staff member. If the school staff member was interested and consented, the researcher arranged a time to speak with them at their convenience. |
| 6. | If parents consented to the researcher meeting with their child, an assent and information letter (see Appendix V) was sent to parents to share with their child. Once this was signed, the researcher liaised with the school and parents to agree an appropriate time to meet with them. |

## Appendix E: Parent Debrief Letter.

### What are the stories of young children, and their families, who have experienced a period of illness / injury in early childhood?

**Thank you** for taking part in the research project. Your contributions are greatly appreciated and will contribute to a better understanding of families experiences following their child's serious hospital admission.

The interview you took part in was designed to allow you freedom to tell your story about your child's hospital admission and how you experienced it. I hope that you enjoyed having the opportunity to reflect and re-tell your story.

Listening to your views helps those working with families to better understand how they can support children and families on their recovery journey.

***What will happen to the information that you have provided?***

Everything we spoke about will be kept confidential and only I will have access to the recordings.
Your interview will be transcribed and anonymised so that you and your child will not be identified.
I will produce a write up thesis for the project which will be accessible on the UEL research repository. If you are interested, I can let you know how to access the thesis.
All of the data will be stored securely and deleted once the project has finished.

***What will happen next?***

I will be in touch to check in with you about my interpretations and to make sure that I have captured everything correctly. Following that, I will go ahead and finalise my write up.

I hope that taking part in this research has been an enjoyable experience for you. However, if you feel affected by what we have spoken about together, the following organisations may be helpful should you wish to speak to someone confidentially for support and guidance about you or your child:

| **Service** | **Contact details** | **On offer** |
|---|---|---|
| Samaritans Free 24 hours helpline: | Call : 116 123<br>jo@samaritans.org<br>https://www.samaritans.org/ | 24 hour available support for those who are struggling and in distress. |
| Family lives | www.familylives.org.uk | Able to signpost to local support groups for parents, offer a range of services related to different concerns for children and families. |

| | | |
|---|---|---|
| MIND | https://www.mind.org.uk/ | Offer short and long term psychological talking therapies and support groups to local residents across the country. |
| You can always contact your GP to talk through any concerns regarding yourself or your child’s mental or physical health. | | |

## Appendix F: Teacher Debrief letter

### What are the stories of young children, and their families, who have experienced a period of illness / injury in early childhood?

**Thank you** for taking part in the research project. Your contributions are greatly appreciated and will contribute to a better understanding of how children who have experienced a serious hospital admission adjusts to school.

The interview you took part in was designed to allow you freedom to tell your story about working with a child who has had a serious injury or illness, and provided a great insight into what they are like. I hope that you enjoyed having the opportunity to reflect and share your story.
Listening to your views helps those working with families to better understand how they can support children and families on their recovery journey, particularly as they transition to school.

***What will happen to the information that you have provided?***

Everything we spoke about will be kept confidential and only I will have access to the recordings.
Your interview will be transcribed and anonymised so that you will not be identified.
I will produce a write up thesis for the project which will be accessible on the UEL research repository. If you are interested, I can let you know how to access the thesis.

***What will happen next?***

I will be in touch to check in with you about my interpretations and to make sure that I have captured everything correctly. Following that, I will go ahead and finalise my write up.

***Support***

I hope that taking part in this research has been an enjoyable experience for you. However, if you feel affected by what we have spoken about together, the following organisations may be helpful should you wish to speak to someone confidentially for support and guidance:

| **Service** | **Contact details** | **On offer** |
|---|---|---|
| Samaritans Free 24 hours helpline: | Call : 116 123<br>jo@samaritans.org<br>https://www.samaritans.org/ | 24 hour available support for those who are struggling and in distress. |
| Education Support Partnership | Free 24 hour helpline: 08000 562 561 | Offer support and guidance to all |

| | | |
|---|---|---|
| | | educational professionals. |
| (LA specific) MIND | https://www.mind.org.uk/ | Offer short and long term psychological talking therapies and support groups to local residents. |
| You can always contact your GP to talk through any concerns regarding your mental or physical health. | | |

**Contact Details**

**If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.**
**Lucy Stone, Email :**

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Mary Robinson, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email : Mary.Robinson@uel.ac.uk.
**Or**
Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk).

## Appendix G: Child Debrief Letter.

Dear _____

Thank you for talking to me.

It was so nice to meet you!

Thank you for showing me your drawing and your award. Thank you for drawing a timeline and talking to me about your life.

If you have any questions you can ask your parents.

I hope you had fun!

I am going to write a story about what you told me and I will share it with your parents.

From Lucy.

## Appendix H: Parent Interview Prompts

Main question: Please tell me about X and their period of illness / injury and what has happened since.

Potential prompts :

Can you tell me about when X went to hospital. (context of illness, how family managed)

How has it been for you and your family since you were discharged?

What has happened since you were discharged? (consider professional input e.g. medical services)

How, if at all, have your thoughts about your experiences changed now that time has passed?

How has X been?

How is X now? (prompt on social, psychological, emotional wellbeing)

What positive and negative things have happened or changed since the hospital admission?

How would you describe X?

Why do you think they are like that?

How has X coped?

What does X think / know about what happened?

How is X at school? Have there been any concerns?

Does X's nursery / school know about what happened?

Has anything come up for you that you had not previously thought about?

Is there anything else important for me to know to understand you and your child's experiences better?

Do you have any questions?

## Appendix I: Teacher Interview Prompts

Main question : Please tell me about (name).

What do you understand of what happened to X (medical history)?
Did you know about their medical history before they came to school?
Was there any preparation or consideration as a result?
Do they ever share about what happened to them?
How have they adjusted to starting ?
How would you describe X?
Why do you think they are like that?
Do you have any concerns about X?
Do you have any questions ?

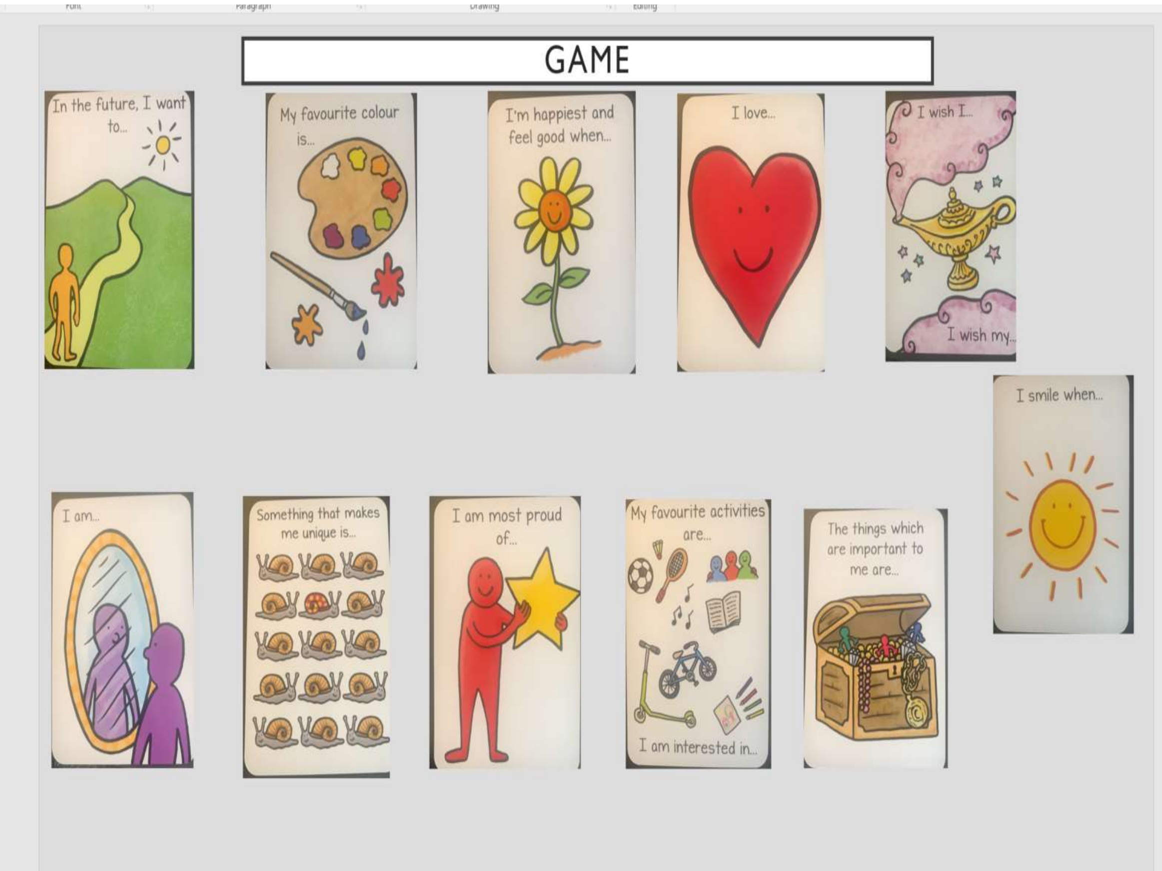
## Appendix J: Child Session Prompts

Creating a story about me
About me now
Likes (across life)
Dislikes (across life)
Memories (if child can comprehend the notion of a memory, explore what things they can remember about their life)
People in my life (family, friends)
School / nursery

**Possible ideas:**

Timeline activity (facilitator draws a time line and puts the child's birth and now as two distinct points) - child can choose what goes on their timeline in-between the time points.
Self-portrait activity / drawings – child encouraged to draw themselves in their life and facilitator can probe and ask about what they put on there and to explore their thoughts about the past, present and future of their life.
Kinetic family drawing
Toy figures – facilitator and child play with toys, child led. Facilitator prompts and encourages the child to explore things about their life or scenarios. Prompts could include what happy, tricky, and sad things happen.
Use of topical toy figures e.g. ambulance, doctor, house.
Sorting activity of things in their life (would rely on parents and or staff to know what is relevant to child).

## Appendix K: Example of the ‘Therapeutic Treasure Deck of Sentence Completion and Feeling Cards’



## Appendix L: Example Transcript – Expert from Sophie's Interview

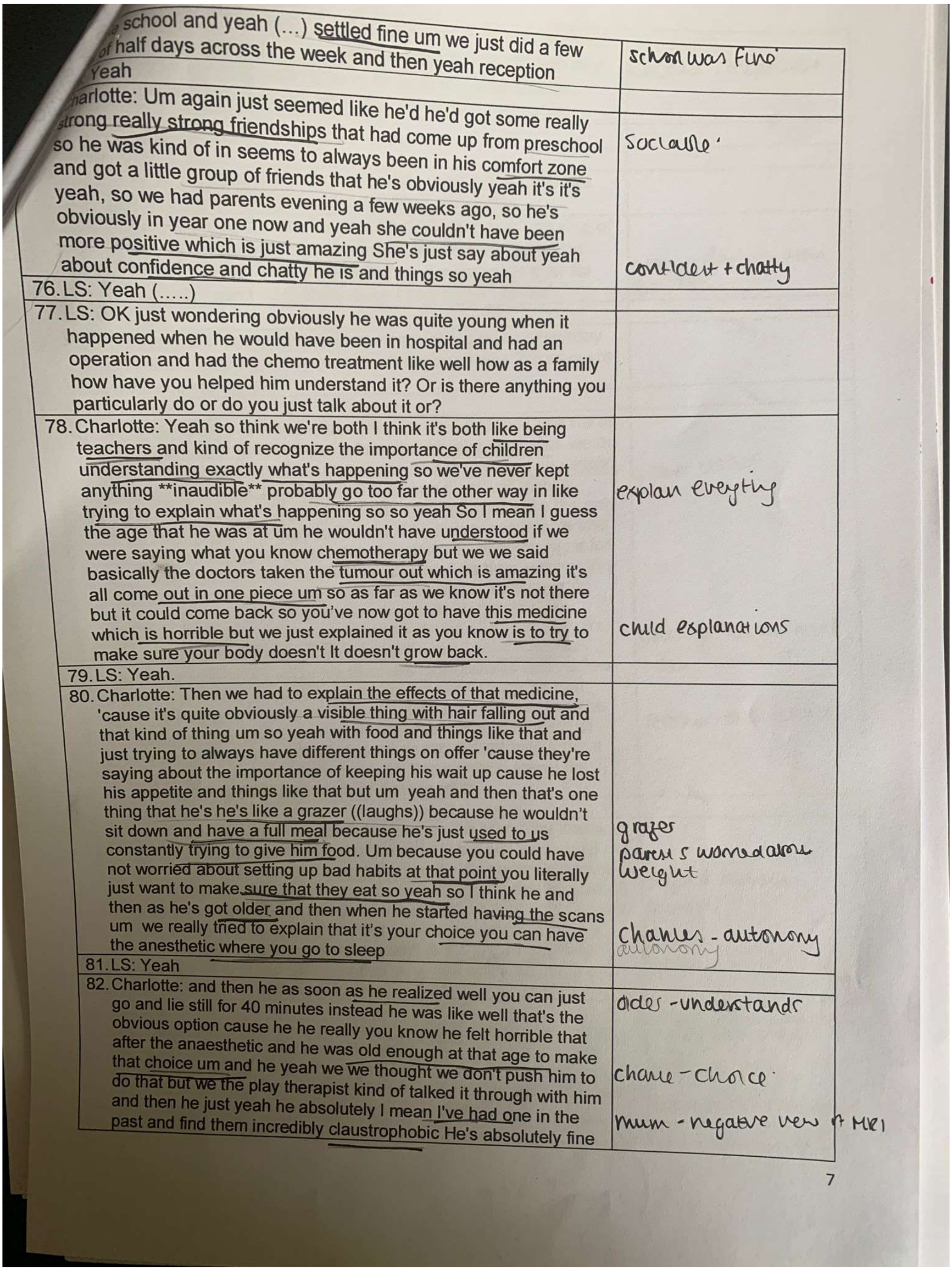
1. LS : How long was he in hospital in total after he was out of the ICU can you remember?
2. Sophie: That's all pretty hazy (.) Another two or three days (.) probably I think (…) In total it wasn't any more than a week and and and I remember thinking I remember thinking when we came home like wow (.) that was he's been through so much in such a short space of time
3. LS Yeah
4. Sophie : He came out like wow that's that (…) Did that really happen?
5. ((general laughter))
6. Sophie : um Yeah, that it was (.) It was very full on it kind of escalated very quickly
7. LS : Yeah
8. Sophie: and then I was in this kind of survival mode for five days (.) In this kind of fight flight way of being and then all of a sudden it was over (…) But obviously we had still be quite cautious with him and with his chest and look after him (….) So I felt anxious leaving hospital because I thought I'm never going back there
9. ((general laughter))
10. Sophie : I'm gonna do everything in my power to prevent something like that happening again (.) It's just horrendous
11. LS : Yeah, how what when you were discharged when you kind of came home you mentioned a diagnosis, did that happen while you were in hospital or did it happen (((in overlap))
12. Sophie: ((in overlap)) no no, there's a story there (…) My mum (.) I think I mentioned that my mom is a retired nurse My mom had said to me I mean my mom is also a bit health anxious so I had to take what my mom said with a pinch of salt otherwise I would have been at the GP with David constantly (…) But my mom had said (.) you know (.) I wonder if it before any of this event occurred (.) I wonder if he ((inaudible)) commented on his swallow basically and she'd said he shouldn't be coughing when he swallows and he wasn't constantly but he will he shouldn't (.) be coughing by this stage and his voice sounds a bit wet often and she kind of picked up on it (…) but I had dismissed it because she picked up on all sorts of other things that turned out to be red herrings
13. LS : Yeah
14. Sophie: Um (…) and once he'd been that poorly, we decided to kind of perceive that as as a family as a possible because we were sort of saying we didn't (.) we were very (…) I'm very conscientious in terms of looking after my kids (.) it just so happens ((laughs)) that they both had awful health conditions through no fault of our own (…) and I'm sure that happens to other people too (…) I'm not saying you know children only get pneumonia because they then neglected or whatever (.) but I I I was puzzled because I'd looked after him so well you know warm and you know it was just so different to how it in before (…) So we thought, what's the harm if Mum is picking up on this and she thinks she thinks he's got dysphasia let's let's check it out (…) he's got no other developmental disabilities (.) so we were like well it's unlikely but let's just let's just check it out so we paid for an assessment privately (.) um with speech and language therapist and yeah I was shocked (…) I was shocked before they even (.)

assessed him in any way because they they they assess children using a video fluoroscopy before they done any of that, she took the history and she was like yeah, I think I think your mom's right. I think it is dysphasia

15. LS : yeah mm mmm

16. Sophie:I was fully prepared to hear her kind of saying no this is a red herring ((laughs)) So I was really shocked but also kind of relieved because if I felt like (.) the blame had been taken away from me somewhat (..) I had it wasn't something that I did wrong (.) it was just that he had this condition that no one knew about. Um what was your question?

## Appendix M: Example of Annotated Interview Transcript



| | |
|---|---|
| school and yeah (…) settled fine um we just did a few of half days across the week and then yeah reception | school was fine |
| Yeah | |
| harlotte: Um again just seemed like he'd he'd got some really strong really strong friendships that had come up from preschool so he was kind of in seems to always been in his comfort zone and got a little group of friends that he's obviously yeah it's it's yeah, so we had parents evening a few weeks ago, so he's obviously in year one now and yeah she couldn't have been more positive which is just amazing She's just say about yeah about confidence and chatty he is and things so yeah | sociable<br>confident + chatty |
| 76. LS: Yeah (…..) | |
| 77. LS: OK just wondering obviously he was quite young when it happened when he would have been in hospital and had an operation and had the chemo treatment like well how as a family how have you helped him understand it? Or is there anything you particularly do or do you just talk about it or? | |
| 78. Charlotte: Yeah so think we're both I think it's both like being teachers and kind of recognize the importance of children understanding exactly what's happening so we've never kept anything **inaudible** probably go too far the other way in like trying to explain what's happening so so yeah So I mean I guess the age that he was at um he wouldn't have understood if we were saying what you know chemotherapy but we we said basically the doctors taken the tumour out which is amazing it's all come out in one piece um so as far as we know it's not there but it could come back so you've now got to have this medicine which is horrible but we just explained it as you know is to try to make sure your body doesn't It doesn't grow back. | explain everything<br>child explanations |
| 79. LS: Yeah. | |
| 80. Charlotte: Then we had to explain the effects of that medicine, 'cause it's quite obviously a visible thing with hair falling out and that kind of thing um so yeah with food and things like that and just trying to always have different things on offer 'cause they're saying about the importance of keeping his wait up cause he lost his appetite and things like that but um yeah and then that's one thing that he's he's like a grazer ((laughs)) because he wouldn't sit down and have a full meal because he's just used to us constantly trying to give him food. Um because you could have not worried about setting up bad habits at that point you literally just want to make sure that they eat so yeah so I think he and then as he's got older and then when he started having the scans um we really tried to explain that it's your choice you can have the anesthetic where you go to sleep | grazer<br>parents worried about weight<br>changes - autonomy<br>autonomy |
| 81. LS: Yeah | |
| 82. Charlotte: and then he as soon as he realized well you can just go and lie still for 40 minutes instead he was like well that's the obvious option cause he he really you know he felt horrible that after the anaesthetic and he was old enough at that age to make that choice um and he yeah we we thought we don't push him to do that but we the play therapist kind of talked it through with him and then he just yeah he absolutely I mean I've had one in the past and find them incredibly claustrophobic He's absolutely fine | older - understands<br>change - choice<br>mum - negative view of MRI |

7

## Appendix N: Example of Organising the Interview Transcripts

Alison's reorganised transcript

| | |
|---|---|
| **Pregnancy** | : Adam was born in January 13th 2 he was um (…) from pregnancy<br>assumed it was from scans we knew it was a twin pregnancy at early stages but at 13 weeks I had a really really heavy bleed and thought that I miscarried but there was still one heartbeat (.)<br><br>and then they said the baby was fine but the scan was (…)<br><br>went for a scan at 20 weeks<br>in my mind it wasn't done correctly ok<br>had already had it in my mind that something was wrong, it was there and there was nothing anyone could do to take that away.<br><br>well so I went for a private scan at mother care baby bond |
| **Adapting to physical differences / condition** | said because I need to know I need to know what I need to learn for my son so I cried because I wanted to know<br><br>didn't put it on him at the beginning and I tell them that I was like nah he can hear its fine and I used to cover his ears when we went out and I used to put hats and I used to put a blanket around so no one would look he was also tube fed when he came home so I was quite insecure about what people would say and what people would think<br><br>I have no regrets you know one thing they I used to think often even if someone did tell me that Adam had these conditions, what difference would it have made? It would have made none. I would have still gone through with the pregnancy and I guess that's the way I need to look at it.<br><br>I didn't change straight away, I still found it hard, I used to hide his ears, he used to have, he still has, you'll see it when you meet him, it flops like this at the bottom **points to lobe** and I used to try and put sello tape to hold it to stay like **holds ear back ** yeah there's certain things that you do<br><br>: and now, Adams got short hair every 3 weeks religiously we go to the barbers and his ears are on show and his hair he doesn't want any of it hes just Adam and it took a while. I couldn't even tell you the timeframe on how long it too, it took me a while to adapt to that and people (…) if Adam didn't have the hearing aids, you wouldn't even notice his ears, but one thing I do when I meet people is look at their ears, it's really strange but its something that you do and wow but um yeah it took me a while to adapt to it. Like his heart condition I didn't understand why um |

## Appendix O: Examples Illustrating the Process of Creating Storied Narratives from Interim Narratives

*The numbers in brackets refer to the original section in the transcripts.*

Rachel's story

| **Interim Narrative** | **Storied narrative** |
|---|---|
| Diagnosis<br>diagnosed with a brain tumor in November (.) so it's just before he turned 2 (3)<br>Intuition<br>Yeah it's literally just like he had a hand spazm and kind of shrieked as if it was a pain and he didn't have a cold or fever you know temperature (144)<br>it wasn't You just knew I just knew straight away that's not right a child doesn't do that um and I was like right (144)<br>it was a Saturday so we took him to the out of hours GP and then he even in between us going there, he did it another couple of times and you could tell the GP was like there's nothing to explain that (144) | Noticed something was wrong<br>Rachel first noticed something was wrong when Charlie started having spasms and shrieking in pain. Rachel knew straight away that something wasn't right, as children don't do that usually. Charlie didn't have a cold or temperature or anything so Rachel took him to the doctors. It was a Saturday so Rachel took Charlie to the out of hours GP and even on that journey, he did it a couple more times. The GP recognised that there's nothing to explain the spasms and suggested they go to A&E. |
| Diagnosis<br>Rachel: Yeah ((laughs)) and I mean we're very lucky that the GP took us seriously (149)<br>t was really quick from um symptoms starting to diagnosis (.) so he um had a lot of hospital visits and appointments and scans in the space of two or three weeks (.) and then he | Lucky diagnosis was quick<br>Rachel feels they were very lucky that doctors took them seriously. When they were at A&E, a consultant walked past Charlie and noticed his spasms as some sort of seizure. Charlie had a CT scan that day and they could see something was not right, so he was sent to the specialist hospital. It was a really quick process from symptoms starting to diagnosis, with lots of appointments and visits in the space of two to three weeks. Charlie was diagnosed with a brain tumour in November, just before he |

| | |
|---|---|
| actually had his surgery at the beginning of that December (4)<br>o I mean it was you know you hear horror stories don't you of children taking years to be diagnosed but it just presented so quickly (147)<br>and luckily the the consultant walked past while we're in the waiting room and saw it and saw it was like a kind of seizure thing and again it was like no that's not right and so he had a CT scan and then they could obviously see something and then they sent us down to [city] (5) | turned two. Rachel feels lucky as she had heard horror stories of children taking years to be diagnosed. |
| **Surgery**<br>So so yeah so we're lucky in terms of location it was obviously somewhere that they could get to without doing damage yeah (158)<br>'cause it's where it was located, but they were more concerned about physical and said it could be long term but actually because of his age and how elastic the brain is there's much higher chance that he would be able to get movement back(156).<br>No I mean obviously 'cause he was so young you can't guarantee but in terms of personality of the baby that he was yeah we didn't feel and the the surgeon did say about where the tumor was located it was more of the physical side and that's why they thought he would lose feeling in his of one whole side of his body as a result of where it was but they | **Surgery**<br>The tumour was located in a part of the brain where they wondered if he might lose feeling in one whole side of his body, but only Charlie's leg was impacted. Due to Charlie's age, his brain elastically is much higher so the surgeons predicted that he would get movement back, which he did. Rachel doesn't feel that the tumour has had any impact on Charlie's personality or memory or anything like that, there were only short-term physical implications. |

| | |
|---|---|
| weren't so concerned about the personality memory type of(154) | |

Laura’s story

| **Ben and Josh treatment** | **Ben and Josh treatment** |
|---|---|
| Uh it's difficult 'cause Ben and Josh Blur into one Josh was still having community nurse come in all the time (26) | Trying to remember the details can be difficult as Ben and Josh’s treatments blur into one. |
| Support too much<br>yeah you do I I don't know I I often – I talked to other families They go Oh we got this support we got that support and I wonder I don't I can't really remember what I was like but I'm quite an independent person and I've got told that by a lot of professionals that you’re just too independent and I found a lot of professionals being involved quite invasive 'cause our lives were so out there like You know we were always in hospital and always changing over and always people in our home So it might not be that the support wasn't there It might be I didn't take up with it I can't quite work out the difference in my head so yeah (30). | Support from professionals too much<br>When Laura has spoken to other families, they have told her that they got support from different people during their illness. Laura can’t remember what it was like for the family. She reflected that it might not be that the support wasn’t there, but that she didn’t take it up.<br>She is quite an independent person and professions have told her that she’s just too independent.<br>Laura found a lot of professionals being involved quite invasive because their lives were so out there. The family were always in hospital and always had people in their home. |
| Types of support<br>hink because we had both boys we decided early on 'cause we just couldn't really keep up with the amount of support (.) which was amazing<br>we were inundated with stuff so we had one friend who sort of coordinated it and like we’d sort of say what we needed to him that week and he would put it it out and then people would (…) **breath in** But it in a way sometimes support was really overwhelming and I found that sometimes I wanted that to stop (32) | Types of support<br>Laura and Tom  received so much support. they were inundated with stuff so they had friends wo coordinated it and got the family what they needed week by week. The support was sometimes overwhelming and Laura found that at times, she wanted it to stop.<br>There were things arriving at their house all day long, maybe three to four packages a day. The admin involved in dealing with even the |

| | |
|---|---|
| Because there were just things arriving at your house all day long like I think probably three or four packages a day, and just the admin involved in dealing with even the recycling I couldn't have a head for at that time. But yeah you you need all sorts of support (.) meals, I don't think I knew what was in my fridge for two years ((laughs)) um let alone if I had made it or not. Right and that was amazing there was always something on our doorstep and just some friends who were willing to just turn up at the drop of a hat to help you with the next new difficult thing you have to deal with that cancer throws at you (34)<br><br>whatever that might have been and so yeah we you realize I think that's even more emotional than the actual thing you're going through is how lovely people are (34) | recycling was too much and Laura didn't have the headspace at the time.<br><br>The family needed all sorts of support. Laura didn't know what was in her fridge for two years, let alone if she had made it or not.<br><br>There was always someone on their doorstep and some friends were willing to just turn up [at the drop of a hat to help with whatever difficult thing cancer threw at them.<br><br>Laura felt that realising how lovely people were was as emotional as the things they were going through. |
| <u>Ways of coping</u><br><br>We wrote a blog  and my husband wrote one one week and I'd write the next to make sense of the process to communicate with family and friends to invite comments I suppose just to - And now it's just really amazing to be able to read it back 'cause sometimes you think what the hell happened 'cause it was so **deep breath in** Insane really um (32)<br><br>Because I think it was our shared like view and it helped us build quite a positive narrative at the time In a really despairing time and I think it wasn't purposeful but it was the way we wrote it helped guide how we were feeling about it and I still feel like (42) | <u>Way of coping</u><br><br>As a way of coping, Laura and Tom wrote a blog. They took turns to write it week by week. Writing the blog was a way of making sense of the process and to communicate with family and friends.<br><br>It is amazing to be able to read it back now because something Laura wonders what the hell happened because the whole experience was so insane.<br><br>The blog was a shared view and it helped Laura and Tom to build a positive narrative during a really despairing time. The way they wrote the blog guided how they were feeling. |

## Appendix P: Ethics Amendment Letter September 2021

**UNIVERSITY OF EAST LONDON**
**School of Psychology**
**REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION**
**FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS**

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

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

**HOW TO COMPLETE & SUBMIT THE REQUEST**

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

**REQUIRED DOCUMENTS**

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

Name of applicant: Lucy Stone

Programme of study: Professional Doctorate Educational and Child Psychology
Title of research: What are the stories of young children, and their families, who have experienced a hospital admission?

Name of supervisor: Mary Robinson

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

| Proposed amendment | Rationale |
|---|---|

| | |
|---|---|
| Age range is to include young children in  lower primary as well as early years. | The focus of the research is on young children who experienced time in hospital before starting nursery or school, therefore children who are in the lower primary in addition to the early years will be included in the research, especially as recruitment will take place in the autumn term, so many children may have already been at school for the past year. |
| Changing the recruitment method to allow recruitment to take placed in other local authorities. | The desired sample may be hard to reach and therefore by widening the sampling pool to include other local authorities, the researcher may find it easier to identify and recruit participants. |
| To allow other professionals in the Local authorities to aid recruitment in addition to the EP service. | The desired sample may be hard to reach and therefore sharing the research with other professionals who work with families may aid recruitment. |
| To allow face to face data collection, particularly for the young children participants. | Due to the age of the child participants, it will be difficult to engage, communicate and develop a rapport with young children via video call as they will not know me. The nature of the activities we will do together will be child led and include drawing, talking, story making and playing with figures and therefore it will be difficult to do this together via video call. |

| **Please tick** | **YES** | **NO** |
|---|---|---|
| Is your supervisor aware of your proposed amendment(s) and agree to them? | X | |

Student's signature (please type your name): Lucy Stone

Date: 27/08/2021

| **TO BE COMPLETED BY REVIEWER** | | |
|---|---|---|
| **Amendment(s) approved** | YES | |
| | | |

**Comments**

Covid-19 risk assessment form was provided for review and approved.
The study advert has some typographical errors.

Reviewer: Trishna Patel

Date: 16/09/2021

## Appendix Q: Ethical Amendment Letter October 2021

**UNIVERSITY OF EAST LONDON**
**School of Psychology**

**REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION**

**FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS**

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

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

**HOW TO COMPLETE & SUBMIT THE REQUEST**

Complete the request form electronically and accurately.
Type your name in the ‘student’s signature’ section (page 2).
When submitting this request form, ensure that all necessary documents are attached (see below).
Using your UEL email address, email the completed request form along with associated documents to: Dr Trishna Patel at t.patel@uel.ac.uk
Your request form will be returned to you via your UEL email address with reviewer’s response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

**REQUIRED DOCUMENTS**

A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
A copy of the approval of your initial ethics application.
Name of applicant: Lucy Stone
Programme of study: Professional Doctorate Educational and Child Psychology
Title of research: What are the stories of young children, and their families, who have experienced a hospital admission?
Name of supervisor: Mary Robinson

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

| Proposed amendment | Rationale |
|---|---|
| Remove criteria 'previously health child' to allow for a wider pool of children to be recruited. | The focus of the research is on young children who experienced time in hospital and many children have a history of medical needs prior to spending time in hospital. |
| Changing the recruitment method to allow online/social media recruitment. | The desired sample is hard to reach and schools and nurseries are not always aware of a child's medical history. Therefore, by widening the recruitment method, hopefully the researcher will have access to a wider research pool and find it easier to identify and recruit participants as parents will be able to choose to take part. |
| | |
| | |

| Please tick | YES | NO |
|---|---|---|
| Is your supervisor aware of your proposed amendment(s) and agree to them? | X | |

Student's signature (please type your name): Lucy Stone

Date: 21/10/21

| TO BE COMPLETED BY REVIEWER | | |
|---|---|---|
| **Amendment(s) approved** | YES | |
| **Comments** | | |

Reviewer: Trishna Patel Date: 26/10/2021

## Appendix R: Title Change Form

School of Psychology Ethics Committee

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

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

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

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

| Required documents | |
|---|---|
| A copy of the approval of your initial ethics application. | YES<br>☒ |

| Details | |
|---|---|
| Name of applicant: | Lucy stoneLucy stone |
| Programme of study: | Professional Doctorate in Child and Educational Psychology Professional Doctorate in Child and Educational Psychology |
| Title of research: | What are the stories of young children, and their families, who have experienced a hospital admission?What are the stories of young children, and their families, who have experienced a hospital admission? |

| | |
|---|---|
| Name of supervisor: | Mary Robinson Mary Robinson |

## Proposed title change

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

| | |
|---|---|
| Old title: | What are the stories of young children, and their families, who have experienced a hospital admission?What are the stories of young children, and their families, who have experienced a hospital admission? |
| New title: | Early Childhood Critical Illness: Exploring the narratives of children, their parents and school staff.Early Childhood Critical Illness: Exploring the narratives of children, their parents and school staff. |
| Rationale: | The new title is much clearer and highlights that the research includes three different groups of participantThe new title is much clearer and highlights that the research includes three different groups of participant |

## Confirmation

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

## Student’s signature

| | |
|---|---|
| Student:<br>(Typed name to act as signature) | Lucy StoneLucy Stone |
| Date: | 21/03/202221/03/2022 |

## Reviewer’s decision

| | | |
|---|---|---|
| Title change approved: | YES<br>☒ | NO<br>☐ |
| Comments: | The new title specifies the three groups of participants included in the study and will not impact the process of how the data are collected or how the research is conductedThe new title specifies the three groups of participants included in the study and will not impact the process of how the data are collected or how the research is conducted | |

| | |
|---|---|
| Reviewer:<br>(Typed name to act as signature) | Dr Jérémy LemoineDr Jérémy Lemoine |
| Date: | 22/03/2022 |

## Appendix S : UEL Data Management Plan

## Appendix T: Parent Information Letter and Consent Form

What are the stories of young children, and their families, who have experienced a hospital admission?

*You and your child are invited to take part in a research project.*
*Before you decide whether you would like to participate, please take some time to read the information below. This explains why the research is being done and what it will involve.*

### ***Who am I?***

My name is Lucy and I am Trainee Educational Psychologist, studying at the University of East London. I am carrying out a project exploring the experiences of young children and their families following a period of serious illness or injury and a hospital admission.

### ***What is the research?***

The research hopes to explore the impact of a serious hospital admission on young children and their families. Being admitted to hospital can be a difficult time for children and their families. Alongside the potential physical impact, the experience may have a significant impact on psychological and social wellbeing.

Previous research in this area has focused on older children who have had a coherent understanding of their illness or injury and subsequent admission to hospital. However, for younger children, who have not developed complex language or understanding skills, little is known about how they come to understand their experiences and how it impacts the child and their family. The research is also interested in how these experiences may impact on a child as they attend school or nursery and whether additional support could be put in place.

### ***Why have I been asked to take part?***

You are invited to take part if you are the parent/carer of a young child whom:

- Experienced a period of serious illness or injury with a hospital admission (e.g. in the paediatric ICU / Critical Care / High Dependency Unit).
- The child is currently attending nursery or school.
- The child is currently in Nursery, Early Years, Reception, Year 1.

I hope that this project will help professionals working with children and their families to better understand the impact of a hospital admission on young children.

**It is up to you whether you choose to take part in this research and you should not feel coerced.**

## *Who will be in this project and what will it involve?*

**Part 1: You as the parent or carer**

- I will contact you directly to organise a date and time to meet.
- We can either meet at a place convenient to you or speak remotely via Microsoft Teams video call. I will record our meeting so that I can accurately recall what has been said.
- During the meeting, I will ask you some questions and encourage you to share about your experiences of your child's illness or injury, their time in hospital, recovery and what life is like now.
- This will take approximately 1 hour – 1.5 hours.

**Part 2: A member of staff from your child's school or early years setting (e.g. Class Teacher, Key Worker)**

- **With your permission**, I will contact your child's school setting and arrange to speak with a member of staff who knows your child well, to gather information about their nursery or school experience.

Gathering information from different perspectives will help to inform best practice for supporting children and their families, particularly within education provisions.

**Part 3: Your child**

- **With your permission**, I would like to facilitate some activities with your child to explore their own life story. This could include, creating a timeline, completing a self-portrait, talking about their likes and dislikes, drawing important people or using toys to act out different scenarios.
- We can arrange a time and place that is convenient to you and your child. I could either visit your child at their nursery or school or meet you and your child in a community space that you feel is suitable.
- This will take approximately 1 hour.

## *Are there any risks to taking part?*

- I am mindful that talking about your child and your experiences may be distressing and evoke some difficult memories. If this is the case, we can stop the meeting at any point or take a break.
- I will provide a list of relevant support services for you to contact if you experience any distress during or after we meet.

## *Are there advantages to taking part?*

- I hope that having the opportunity to share and reflect on your journey may be positive and help you to gain new insight into your experiences.
- Your involvement will help me to better understand how professionals can support families who have been through a similar experience.

## *Will my taking part in the research be kept confidential and can I withdraw?*

- Your privacy and safety will be respected at all times.
- Nobody will be able to identify you and your child.
- All information reported as part of the write up of the research will be anonymous and will not include names, schools or any personal or identifiable details. If you have any concerns or are unsure, you are welcome to speak with me before the interview.
- Both you and your child have the right to withdraw from the research at any time without explanation of consequence until data analysis is completed. At this point, all information gathered will have been anonymised and I will not know who has said what.

### *What will happen to the information collected?*

- I will keep all of the recordings taken during our meetings on my secure university drive. Once I have completed data analysis, they will be deleted.
- I will keep your consent forms and personal contact details securely on my university drive. Once I have completed data analysis, these will be deleted.
- Once I have collected all of the stories from parents/carers, children and staff who take part, the anonymised results of this research will be written up as a thesis as part of my Doctorate in Educational Psychology.
- The thesis will be available as part of the UEL's research repository for 5 years and will include anonymised excerpts of data from the research.

### Contact Details

**If you would like further information about my research or have any questions or concerns, please contact me: Lucy Stone, Trainee Educational Psychologist.**

### *Ethical approval*

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

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Mary Robinson, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email : Mary.Robinson@uel.ac.uk. Or Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.lomas@uel.ac.uk).

I have read the information sheet relating to the above research project in which I have been asked to participate and have been given a copy to keep. The nature and purpose of the research has been explained to me, and I have had the opportunity to discuss the details and ask any questions about the project. I understand what is being proposed and the details of my involvement have been explained to me.

I understand that my and my child's involvement in the project will remain strictly confidential. Only the researcher involved in the study will have access to the data. It has been explained to me what will happen once the research has been completed.

| **Please tick the boxes to indicate your consent:** | ✓ |
|---|---|
| I hereby freely and fully consent to participate in the study which has been explained to me : | |
| I hereby freely and fully consent to my child taking part in the study : | |
| I consent to the researcher contacting my child's early years provision to contact a member of staff who knows my child to be interviewed as part of the research : | |
| Having given my consent, I understand that I have the right to withdraw myself and or my child from the study at any time during and up until the point of data analysis, without disadvantage to myself and without obligation to give any reason : | |
| I consent a copy of the thesis being available on the UEL Research Repository and containing anonymised experts of transcripts. It will be kept for 5 years at which point it will be reviewed in line with the UEL Data Management policy and kept or destroyed : | |
| I consent to anonymised excerpts of transcripts being shared as part of the research dissemination which may include conference presentations or research papers : | |

*Participants name:*

*Participant's Signature:*

## Appendix U: Staff Member Letter and Consent Form

### What are the stories of young children, and their families, who have experienced a period of illness / injury in early childhood?

You are invited to take part in a research project. Before you decide whether you would like to participate, please take some time to read the information below. This explains why the research is being done and what it will involve.

### Who am I?

My name is Lucy Stone, and I am Trainee Educational Psychologist studying at the University of East London. As part of my training, I am carrying out a project exploring the experiences of young children and their families following a period of serious illness or injury and a hospital admission.

### What is the research?

The research hopes to explore the impact of a serious hospital admission on young children and their families. Being admitted to hospital can be a difficult time for children and their families, alongside the potential physical impact, a traumatic experience can have a significant impact on psychological and social wellbeing.

Research in this area has previously focused on older children who have had a coherent understanding of their illness or injury and subsequent admission to hospital. However, for younger children, who have not developed complex language or understanding skills, little is known about how they come to understand their experiences and how it impacts the child and their family. The research is also interested in how these experiences may impact on a child as they start school or nursery and whether additional support could be put in place.

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

### Why have I been asked to take part?

You are invited to take part as you currently work with a child who has experienced a period of illness / injury and a hospital admission during their early childhood and has since started school.

I hope that this project will help professionals working with children and their families to better understand the impact of a hospital admission on young children. Gathering information from different perspectives will help to inform best practice for supporting children and their families, particularly as they transition to an education provision.

With your help, I would like to explore the experience of children who have had a hospital admission as they adjust to school life.

**It is up to you whether you choose to take part in this research and you should not feel coerced**.

### Who will be in this project and what will it involve?

### Part 1: Yourself as a member of staff from a school or Early Years setting (e.g. Class Teacher, Key Worker).

If you would like to take part, I will contact you to find out when is a convenient time to organise a meeting. Due to the current restrictions in light of Covid-19, this will take place over Microsoft Teams. / We can arrange to meet in a place that is convenient to you. During the meeting, I will ask you some questions about the child and their adjustment to nursery or school. It does not matter if you are not particularly aware of the child's medical history, as the intention is to explore how the child is functioning now and what they are like at nursery or school.

### Part 2: Parents or carers

### Part 3: The child

### Will my taking part in the research be kept confidential and can I withdraw?

Your privacy and safety will be respected at all times.
Nobody will be able to identify you or any other participant.
All information reported as part of the write up of the research will be anonymous and will not include names, schools or any personal or identifiable details. If you have any concerns or are unsure, you are welcome to speak with me before the interview.
You have the right to withdraw from the research at any time without explanation of consequence until data analysis is completed. At this point, all information gathered will have been anonymised and I will not know who has said what.

### What will happen to the information collected?

I will keep all of the recordings taken during our meetings on my secure university drive. Once I have completed data analysis, they will be deleted.
I will keep your consent forms and personal contact details securely on my university drive. Once I have completed data analysis, these will be deleted.
Once I have collected all of the stories from parents/carers, children and staff who take part, the results of this research will be written up as a thesis as part of my Doctorate in Educational Psychology.
The thesis will be available as part of the UEL's research repository for 5 years and will include anonymised excerpts of data from the research.

### Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me: Lucy Stone, Trainee Educational Psychologist.

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Mary Robinson, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email : Mary.Robinson@uel.ac.uk.
**Or**
Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk).

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## Consent Form

I have read the information sheet relating to the above research project in which I have been asked to participate and have been given a copy to keep. The nature and purpose of the research has been explained to me, and I have had the opportunity to discuss the details and ask any questions about the project. I understand what is being proposed and the details of my involvement have been explained to me.

I understand that my involvement in the project will remain strictly confidential. Only the researcher involved in the study will have access to the data. It has been explained to me what will happen once the research has been completed.

| **Please tick the boxes below to indicate your consent:** | ✓ |
|---|---|
| I hereby freely and fully consent to participate in the study which has been explained to me : | |
| Having given my consent, I understand that I have the right to withdraw myself from the study at any time during and up until the point of data analysis, without disadvantage to myself and without obligation to give any reason : | |
| I consent a copy of the thesis being available on the UEL Research Repository and containing anonymised experts of transcripts. It will be kept for 5 years at which point it will be reviewed in line with the UEL Data management policy and kept or destroyed : | |
| I consent to anonymised excerpts of transcripts being shared as part of the research dissemination which may include conference presentations or research papers : | |

*Participants name:*
*Participant's Signature:*
*Date:*
*Email address:*

## Appendix V: Child Information Letter and Assent Form

Hello! My name is Lucy.

*Picture of researcher*

I am going to meet you (edit accordingly).

We can do some drawing and talking.

I would like to know all about you!

We might draw:

A picture of you
A picture of your family
A picture of your friends

We might talk about :
What you like to do ?
Who is special to you?
What is school like?

We might play with toys too!

**Please tick the box if an adult has explained what will happen :**

| | ✓ |
|---|---|
| An adult will help me draw a time line and some pictures. | `<br>- |
| Lucy will ask me questions about things I like and don't like. | |
| I can choose to show Lucy anything that is special to me. | |
| An adult will be with me and I can stop whenever I want to. | |
| I can choose what we do together e.g. play, draw, talk. | |

**Name :**

**Date :**

## Appendix W: Timeline of Research

| Date | Research Phase |
|---|---|
| **May 2021 – December 2021** | **Recruitment of participants**<br>- Contact made with schools in the researcher's LA<br>- Adapted ethics to aid recruitment<br>- Advertised online |
| **November 2021 – December 2021.** | **Recruitment of participants**<br>- Four parents made contact with the researcher.<br>- Researcher spoke with parents and gained consent. |
| **November 2021** | **Data collection began.**<br>Interviewed parents A and B. |
| **December 2021** | **Data collection continued.**<br>- Interviewed parent C and D.<br>- Interviewed child D. |
| **January 2022- February 2022** | **Recruitment continued.**<br>Researcher contacted schools and teachers recruited. |
| **February2022** | **Data collection continued.**<br>- Interviewed teacher A, B, C and D.<br>- Interviewed child A and D. |
| **February 2022** | **First stage of analysis**<br>- Transcription<br>- Re-storying |
| **March 2022** | Member checking with all parents. |

| | |
|---|---|
| **March – April 2022** | **Second stage of analysis -**<br>Identification of narrative themes. |
| **March – April 2022** | Completed thesis write up. |

## Appendix X: An overview of the mapped narrative themes subsequent themes and sub themes across the parents stories

| **Rachel** | **Alison** | **Laura** | **Sophie** |
|---|---|---|---|
| Onset of illness | Something was wrong in pregnancy – parent intuition | Onset of illness | Onset of illness was stressful |
| Parent intuition | Support from family relationships | Parent intuition | A&E admission |
| Quick diagnosis | School are supportive | Treatment worst part | Impact on her as a mother |
| Treatment was the worst part | Medical staff and positive relationships | Grumpy potato | Emotional gult and regret |
| Support was important | Charity support groups and other families | Emotional regulation and processing | Dark moments in hospital |
| Lack of support from medical staff | Emotional impact as a mother | Fearful of being ill | Happy ending |
| Impact of support from charity | Guilt | Nature vs nurture | Worst thing that ever happened |
| Access to families | Depression | Everything changed | Communication was important |
| Gaps in support | Challenge of uncertainty and unknown | Brother had cancer | Supported to feel part of the team |
| School are supportive | Worst thing that ever happened | Brother passed away | Uncertainty around prognosis |
| Surgeon was a hero | normality | Hard to adjust at school | Parent as a caregiver 24/7 |
| Communication is important | Journey to accepting diagnoses | Changed as a parent | Family priority not to return to hospital |
| Frustration with communication | Adapting | Practical and logistical support | Keep him safe |
| Mixed communication | Grateful and perspective shift | Support was overwhelming | Impacted family – not return to work |
| Charlie's memories and understanding | Communicating with child friendly language | Clear communication is key | No more children |
| Child friend language | Not ready to explain it all | Follow bens lead | Starting school was fine |
| Important to be honest and open | Adams asking questions changing with age | Unsure what he knows | Involved professionals |
| Researcher and advocate | Resilience | Asks random questions | Age was a protective factor |

| | | | |
|---|---|---|---|
| Giving medicine at home | He has met all expectations | Mixed up with brother | Use child friendly language |
| Wider family impacted – disrupted routines | Part of who he is | Ben draws to communicate | Talk about it as a family |
| Sibling most effected | Looking to the future | His understanding will come with time | Coping and sharing information with others |
| Priority was being together | Worried forever | Risk of cancer returning | |
| Overcoming challenges | Look forward to surgeries | Looking at the positives | |
| Aversion to medicine | No more children | Magical moments | |
| Lots of strengths | Family dynamic changed | Coping mechanisms | |
| Perspective shift | Impact on his sleep | | |
| Gratitude | Ongoing care needs | | |
| Want to be at home | Settled at school well | | |
| Age as a protective factor | | | |
| Understanding is changing with age | | | |
| Processing death | | | |
| Aware of seriousness of scans | | | |
| Charlie at school | | | |
| Worries about future | | | |

| **Combined Narrative themes / sub-themes parents** | |
|---|---|
| **Symptoms and admission to hospital** | Parent intuition |
| | Admission to hospital |
| | Treatment was hideous |
| **Emotional journey** | Managing uncertainty |
| | Blame and guilt |
| | Happy endings |
| | Grieving son |
| **How they coped** | Sense of perspective and being grateful |
| | Focus on the magical moments |
| | Sense of normality |
| | Helping others |
| | Everything changed |
| | Familiarity and access to other families |
| | Priorities changed |
| **Everything changed** | Changed routine dynamic |
| | Parents roles |
| | Relationships |
| | Perfect storm for Christopher |
| | No more children |
| | Role as a parent |
| **Experiences of support** | Professionals have power |
| | Lack of support and guidance |
| | Gaps in support |
| | Charity support |
| | Support from school |
| | Communication makes a difference |
| **Impact on the child** | Emotional implications |
| | Child at school |
| | Age as a protective factor |
| | Strengths out of adversity |
| | Physical implications |
| **Honest and open communication** | Part of their life story |
| | Changing with age |
| | How we communicate |
| **Worries and hopes for the future** | Ongoing care and changes |

## Appendix Y: An overview of the mapped narrative themes subsequent themes and sub themes across the children's stories

| **Adam** | **Charlie** | **David** |
|---|---|---|
| What happens in a hospital | My brain tumour is unique | Going to hospital |
| Medical equipment | I'm a survivor | My flap is unique |
| My hearing aid | Gaps in understanding | Uncertainty about what happened |
| Adam's life | Symptoms and diagnosis | Memories of oxy meter |
|  | Horrible medical procedures | Memories of dad at hospital |
|  | Memories of hospital room | My thickener |
|  | Learning to walk again with brother | My interests and football |
|  | Brain tumour is one of my life events |  |
|  | Important things in my life |  |

| **Combined Narrative themes / sub-themes children** |  |
|---|---|
| ***Knowing the facts*** | Confusion and uncertainty |
|  | Parents fill the gaps |
| ***My memories*** | Horrible procedures |
|  | Significant others |
|  | Places and equipment |
| ***Identity*** | I'm a survivor |
|  | Just another event |
|  | All he's known |
| ***Now and the future*** | Ongoing care |
|  | Getting on with my life |

## Appendix Z: An overview of the mapped narrative themes and sub themes across the teachers stories

| Tracy | Mark | Sarah | Mary |
|---|---|---|---|
| **Adam doesn't stand out in the class** | **Ben doesn't stand out as different** | **Feeling lucky to work with him** | **Wouldn't have any idea** |
| **Adam has strengths** | **Friendships** | **Charlie and his friends** | **Knowledge of his condition** |
| **Impact on his learning** | **Unsure if any impact – so young** | **Parents have helped him** | **David doesn't talk about it** |
| **Adam fits in** | **Wouldn't have a clue meeting him**<br>**Ben is stable** | Unsure if any impact | |
| **Zoom calls with the hospital** | **Treating him like everyone else** | **All staff are aware** | |
| **Supportive family and close relationships** | **Talking about his brother, Josh** | **Charlie talking about his brain tumour** | |
| **School knowledge of his conditions** | **Ben doesn't talk about his brain tumour** | | |
| **Talking with Adam about his condition** | **School are supportive** | | |
| | **Starting school** | | |
| | **Ben has always been fine** | | |

| **Combined Narrative themes / sub-themes teachers** | |
|---|---|
| **Impact of the illness** | **They don't stand out**<br>**Child's positive attributes and strengths**<br>**Age as a protective factor**<br>**Unclear if any impact** |
| **What do staff know** | Staff are aware across the school |
| | Preparation |
| | Children talk about it at school |
| | Children don't mention it |

| | |
|---|---|
| **The future** | Uncertainty about the future<br>Ongoing care needs |
| **Supporting parents** | |

## Appendix AA: An overview of the mapped narrative themes and sub themes combined across all participants

| Theme | Parent sub theme | Teacher sub theme | Child sub themes |
|---|---|---|---|
| **The illness** | Parent intuition | | |
| | Admission to hospital | | |
| | Treatment was hideous | | |
| | Managing uncertainty | | |
| | Blame and guilt | | |
| **Coming to terms with the new reality** | Journey to acceptance | | |
| | Part of their life story and identity | | Part of their life story and identity |
| | Grieving son | | |
| | Sense of perspective and gratitude | | |
| | Focus on the magical moments | | |
| | Sense of normality | | |
| | Other families | | |
| | Changes to family dynamic and roles | | |
| | Relationships | | |
| | Perfect storm for Christopher | | |
| | No more children | | |
| **Experiences of support** | Communication makes a difference | | |
| | Lack of professional support and guidance | | |
| | School support | Support from school | |
| **Impact of the illness on the child now** | Present and ongoing needs | | |
| | Nature vs nurture | Unclear | |
| | Child at school | | |
| | Age as a protective factor | Age as a protective factor | |
| | Strengths out of adversity | Positive strengths | |

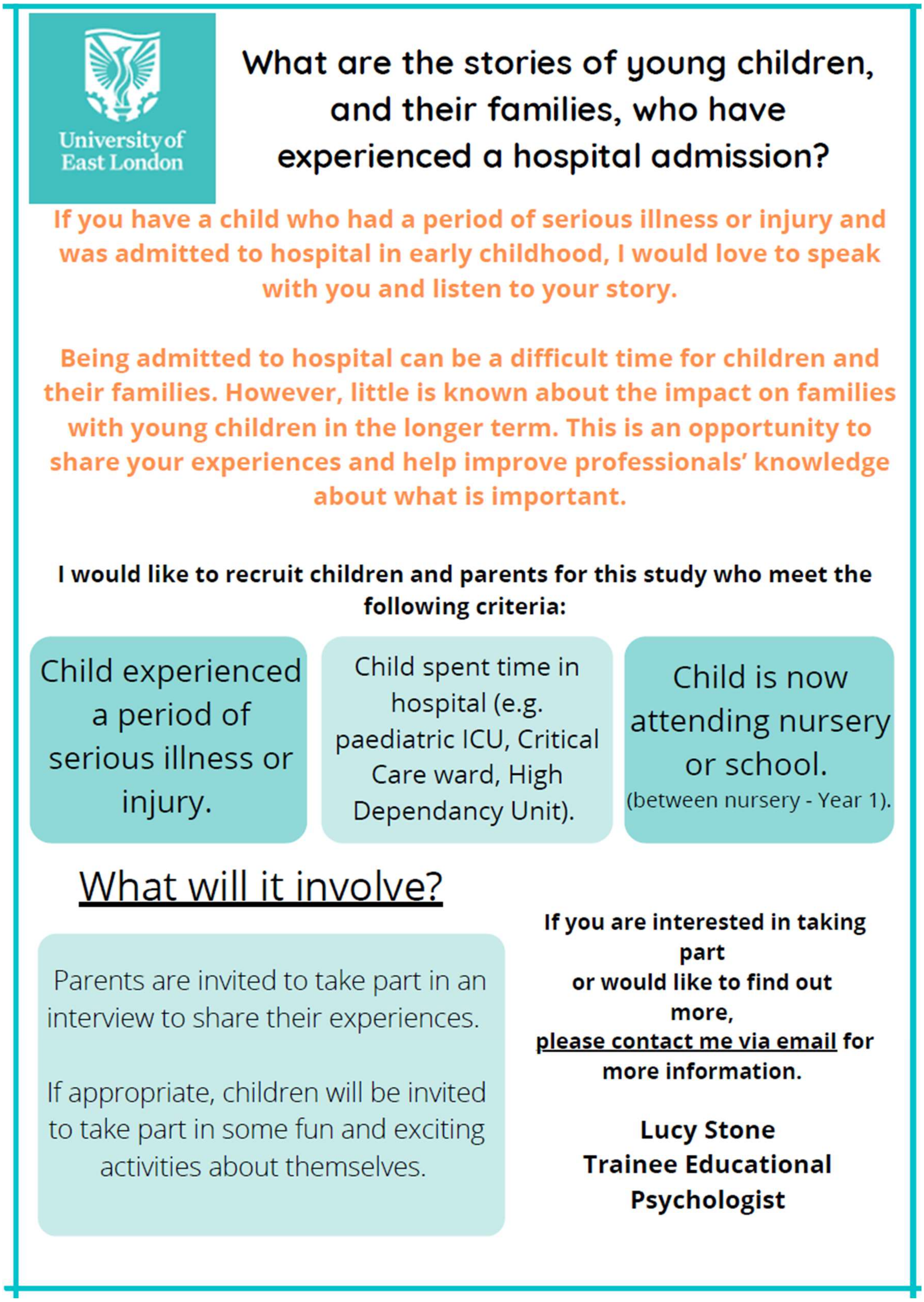
| | | | |
|---|---|---|---|
| | | and attributes | |
| **Sharing information – communication and understanding** | Changing with age | | |
| | How it is communicated and understood | | How and what is communicate |
| | Confusion and uncertainty | | Confusion and uncertainty |
| | Specific memories | | Memories related to specific object/people/places |
| | Teacher’s understanding | Child talking about it at school<br>What schools know | |
| | | | |
| | The future | | |
| **The future** | Ongoing care and changes | Ongoing medical care | Ongoing medical care<br>Horrible procedures |
| | | | |
| | The future | | |

## Appendix AB: Final Narrative themes and sub themes for all participants

| **Theme** | **Sub themes** |
|---|---|
| **The illness** | Parent intuition |
| | Admission to hospital |
| | Treatment was hideous |
| | Managing uncertainty |
| | Blame and guilt |
| **Coming to terms with the new reality** | Journey to acceptance |
| | Part of their life story and identity |
| | Grieving son |
| | Sense of perspective and gratitude |
| | Focus on the magical moments |
| | Sense of normality |
| | Other families |
| | Changes to family dynamic and roles |
| | Relationships |
| | Perfect storm for Christopher |
| | No more children |
| **Experiences of support** | Communication makes a difference |
| | Lack of professional support and guidance |
| | School support |
| **Impact of the illness on the child now** | Present and ongoing needs |
| | Nature vs nurture |
| | Child at school |
| | Age as a protective factor |
| | Strengths out of adversity |
| **Sharing information – communication and understanding** | Changing with age |
| | How it is communicated and understood |
| | Confusion and uncertainty |
| | Specific memories |
| | Teacher’s understanding |
| **The future** | Ongoing care and changes |

# The future

## Appendix AC: Recruitment Poster



University of East London

### What are the stories of young children, and their families, who have experienced a hospital admission?

**If you have a child who had a period of serious illness or injury and was admitted to hospital in early childhood, I would love to speak with you and listen to your story.**

**Being admitted to hospital can be a difficult time for children and their families. However, little is known about the impact on families with young children in the longer term. This is an opportunity to share your experiences and help improve professionals' knowledge about what is important.**

**I would like to recruit children and parents for this study who meet the following criteria:**

Child experienced a period of serious illness or injury.

Child spent time in hospital (e.g. paediatric ICU, Critical Care ward, High Dependancy Unit).

Child is now attending nursery or school. (between nursery - Year 1).

### What will it involve?

Parents are invited to take part in an interview to share their experiences.

If appropriate, children will be invited to take part in some fun and exciting activities about themselves.

**If you are interested in taking part or would like to find out more, please contact me via email for more information.**

**Lucy Stone**
**Trainee Educational Psychologist**