

**IN HOSPITAL BUT NOT FORGOTTEN: AN EXPLORATION INTO CHILDREN AND YOUNG
PEOPLE'S NARRATIVES ABOUT THEIR EXPERIENCES OF HOSPITALISATION AND HOSPITAL
SCHOOL**

By

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A thesis submitted to The University of Birmingham

For the Degree of Applied Educational and Child Psychology Doctorate

VOLUME ONE

School of Education

The University of Birmingham

December 2015

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ABSTRACT

Today, increasing numbers of children and young people (CYPs) live with chronic health conditions, a fact reflected in recent UK legislation which highlights the necessity of supporting these CYPs to fully access education. This study explores the experiences and perspectives of children and young people with chronic conditions (CYPCCs) regarding hospitalisation and hospital school. A narrative methodology was selected to explore the experiences of five hospitalised CYPCCs (aged 12 to 16 years) in addition to the meanings they ascribed to these experiences.

Findings contribute important insights into CYPCCs' experiences of hospitalisation in relation to the following: family, personal growth, health-related identity, relationships, coping, unpredictability and uncertainty and medical intervention and physical pain. This research makes a unique contribution to the field, in relation to the substantive topic (how CYPCCs perceive educational experiences in hospital settings), and the original application of a narrative research methodology. I argue the necessity for professionals to recognise CYPCCs as a potentially vulnerable group. Ethical issues concerning access to hospitalised CYPCCs for research purposes are highlighted and the value of narrative research with CYPs is endorsed. Implications for professional practice and research are discussed which seek to improve the educational opportunities, experiences and outcomes for CYPCCs.

DEDICATION

For Suzan, Farah, Sumayah, Rose and Sajid who shared the gift of their personal stories with me.

And for those children and young people who face similar challenges in their daily lives but do not get the opportunity to voice their experiences.

ACKNOWLEDGEMENTS

I would like to thank my university tutor, Colette Soan, for her support, supervision and insight throughout the three years of my doctoral training. I am appreciative of her input, particularly during the challenging points of this research.

I would also like to thank Sue Morris, Programme Director, for her unwavering support and encouragement during my three years of study.

Special thanks go to my family, including my mother and sister, Kara, for their love, encouragement and patience. In particular, I thank my twin sister, Zoë, for always being there for me and for being my number one. She has given me strength and courage I did not know I had.

Thank you to my friends, Fiona, Gemma, Jen, Emma, Janet and Helen for the academic and emotional peer support they have provided, particularly towards the end of this journey.

Finally, thanks go to the Educational Psychologists who, through their knowledge, kindness and dedication continue to inspire me for my future professional career.

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ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
BERA	British Educational Research Association
BPS	The British Psychological Society
CC/CCs	Chronic condition/s
CYP/CYPs	Child or young person/ children and young people
CYPCC/CYPCCs	Child or young person with a chronic condition/ children and young people with chronic conditions
DfE	Department for Education
DfES	Department for Education and Skills
DoH	Department of Health
EP/EPs	Educational Psychologist/s
FOI	Freedom of Information
HCPC	Health and Care Professions Council
HS/HSs	Hospital school/s
LA/LAs	Local authority/authorities
NHS	National Health Service
PRUs	Pupil Referral Units
PTSD	Post-Traumatic Stress Disorder
REC	Research ethics committee
RQ/RQs	Research question/s
SEN	Special educational needs
SEND	Special educational needs and disabilities
TEP	Trainee Educational Psychologist

1.0. INTRODUCTION

1.1. Background for research

In the UK today, there are steadily growing numbers of children and young people (CYPs) living with chronic health conditions, illnesses characterised by their longevity and impact on quality of life (National Public Health service for Wales, 2006). This includes illnesses such as asthma, cancer, diabetes, epilepsy and cystic fibrosis. Evidence suggests that more CYPs survive medical health conditions thanks to developments in medical technology (Mukherjee et al., 2002; Sloper and Lightfoot, 2004), meaning that children are surviving chronic conditions (CCs) and living into adulthood, more now than ever before (Stam et al., 2006; Maslow et al., 2011). Yet Woodgate (1998) suggests that growing up with a chronic condition (CC) can be burdensome for CYPs, owing to additional stressors such as activity limitations, hospitalisation, school absences, pain and medications.

1.1.1. National and political context

Recent global epidemiological studies indicate that the numbers of CYPs with CCs vary from 7.3% (Blackburn et al., 2010)¹ to 10% (Yeo and Sawyer, 2005)² and some studies even suggest that 15% of CYPs (in Germany and England) live with a CC³. Of course CCs vary

¹ Blackburn et al. (2010) indicate that 7.3% CYPs are disabled in line with the definition stated in the Disability Discrimination Act (1995), which defines disability in terms of CYPs experiencing a long-standing and limiting illness or disability (for 12 months or longer), and experiencing one or more significant difficulties or health problems.

² Yeo and Sawyer (2005) propose that 10% of CYPs will have a CC that is severe enough to significantly limit their daily life and require additional care.

³ Pinquart (2013) indicate that the figure is as high as 15% regarding CYPs who live with a CC. This is supported by research from the Health Behaviour in School-aged Children (HBSC) study, which posits that 15% of school

widely in the UK, in terms of the nature of the condition, the treatment regimen, necessity and frequency of hospital visits and ultimately the impact on the child or young person (CYP) and their family. An Association for Young People's Health (AYPH) publication summarises the national prevalence of CCs, providing a breakdown of some conditions (Treadgold, 2012) (see Table 1).

Table 1: Statistics regarding the prevalence of selected chronic conditions for CYPs in the UK taken from Treadgold's (2012) report

Chronic condition	Prevalence
Asthma	<ul style="list-style-type: none"> ○ Approximately 1 in 11 CYPs (approximately 1.1. million) in UK have asthma, making it the most common long-term medical condition.
Cancer	<ul style="list-style-type: none"> ○ Approximately 1 in 500 CYPs in the UK develop a form of cancer by the age of 14 years. ○ It is the most common cause of death from disease for CYPs.
Diabetes	<ul style="list-style-type: none"> ○ Approximately 29,000 CYPs in the UK have diabetes, with about 26,500 of them having Type 1 diabetes, 500 having Type 2 diabetes and 2000 with the diagnosis unknown. ○ The prevalence for Type 1 diabetes is 1 in 700-1000 CYPs and the peak age for diagnosis is between 10-14 years.
Epilepsy	<ul style="list-style-type: none"> ○ Approximately 60,000 CYPs in the UK have epilepsy, which is 10% of the overall total population of people with epilepsy in the UK.

Studies demonstrate that more children and young people with chronic conditions (CYPCCs) and/or physical disabilities are now educated in mainstream schools as a result of trends in education, towards inclusive education and practice (Bunn, 2015). During hospitalisation, CYPCCs miss school, but they are entitled to receive education from 'hospital schools' to maintain continuity of education (DfE, 2013a; DfE, 2014). Hospital education is legally defined by The School and Early Years Finance (England) Regulations (2013, p. 5) as:

students aged 11-15 years in England reported having a diagnosis of a long-term illness, disability or medical condition (Brooks et al., 2011).

“Education provided at a community special school or foundation special school established in a hospital, or under any arrangements made by the local authority under Section 19 of the 1996 Act (exceptional provision of education) where the child is being provided with such education by reason of a decision made by a medical practitioner.”

Although I use the term ‘hospital school’ (HS) throughout this paper for ease of reference, the term is not recognised in law, as these schools are typically defined as special schools or Pupil Referral Units (PRUs). However, hospital education which provides for CYPs with medical needs, differs from typical special schools which provide for CYPs with Special Educational Needs (SEN), and PRUs which deliver provision for CYPs who have been permanently excluded (DfE, 2013b). Hospital education is delivered in various contexts such as general or district hospitals, specialist hospitals catering for chronically ill or long-stay patients, established PRUs or special schools, or at home (DfE, 2013b). Sourced through my Freedom of Information (FOI)⁴ request, Table 2 presents the number of CYPs in England who attended HSs from 2010-2015, although these are highly likely to be an underestimate (see footnote 5).

Table 2: Number of pupils in general hospital schools in England according to the School Level Annual School Census (SLASC GHS)⁵

Year	Number of general hospital schools	Number of pupils (aged 16 years and under)
2010	13	180

⁴ The Freedom of Information Act (2000) is an Act of Parliament that provides the public with a "right of access" to information held by UK public authorities.

⁵ These figures account for a very specific subset of schools and are in effect special schools contained within hospitals. There are currently 11 of these schools in nine local authorities (LAs) across England. Other schools contained within hospitals do not have a special designation as a general HS. Therefore the figures collected from general HSs by the department do not cover every child being educated whilst in hospital. LAs have a responsibility to provide education for children in long term hospital stays and many LAs have PRUs and alternative provision providers in hospitals which are not considered to be general HSs, and are therefore unaccounted for in these figures. LAs can also provide education via other means, such as with visiting tutors. Furthermore, SLASC GHS provides a snapshot of the pupils in general HSs and there may be others who have attended whilst in hospital who were not recorded on the census.

2011	13	1,365
2012	12	1,340
2013	12	1,420
2014	11	1,195
2015	11	1,230

From a national perspective, the 1944 Education Act first acknowledged the necessity for education outside of the school setting, meaning that home tuition and teachers in hospital settings became more prevalent, particularly due to the practicalities of CYPCCs attending school at that time (Wiles, 1987).

More recently, Section 19 (1) of the 1996 Education Act imposed a statutory obligation for CYPs with medical needs to access appropriate education. The legislation states:

“Each local education authority shall make arrangements for the provision of suitable education at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them.”

The statutory guidance produced by the DfE (2013a), ‘Ensuring a good education for children who cannot attend school because of health needs’, which replaced the DfES (2001) statutory guidance ‘Access to Education for Children and Young People with Medical Needs’, further explains this legal duty. In this document it states that CYPs with health needs should receive ‘good quality education’ commensurate with that of mainstream schooling in addition to the support required to overcome obstacles to achievement (DfE, 2013a). This is an entitlement for all students with medical needs, including those who are unable to attend school at all, and those who attend school intermittently.

In summary, the DfE (2013a) guidance places responsibility on the LA to ensure that for CYPs with health needs, disruption to their education is minimised and continuity to their education is of utmost importance. The guidance emphasises the need for collaborative working for the best interests of the CYP, for example the LA with relevant agencies and medical professionals regarding identification and intervention regarding suitable provision. A detailed summary of the LA's key duties, as defined by the statutory guidance of 2013 is outlined in Appendix 1. Under the Equality Act (2010), some complex and/or long-term medical conditions may be deemed a disability, which implies that CYPs must not be discriminated against. LAs must therefore provide reasonable adjustments to lessen disadvantage endured by disabled CYPs.

Most recently, Section 100 of the Children and Families Act (2014) obligates maintained schools, academies and PRUs to make provisions to support students with medical needs in their settings. The statutory guidance, 'Supporting pupils at school with medical conditions' (DfE, 2014), which supports the Children and Families Act, states that educational settings must support CYPs with medical conditions, in terms of both physical and mental health, to be actively involved in school life and achieve academically. Health and social care professionals, parents and students themselves should be consulted to ensure the CYP's needs are effectively supported. Schools must establish a policy in relation to meeting the needs of pupils with medical conditions, which includes the use of individual healthcare plans, with designated staff accountable for each pupil with a medical condition. The guidance states that school policies should consider the management of medication, emergency procedures and ways to guarantee that CYPs with medical conditions are

involved in trips (DfE, 2014). Ofsted regard children with medical conditions as a vulnerable group, alongside others, and schools are judged in relation to how the health, emotional and academic needs of this group are met, to promote positive outcomes for CYPCCs (Ofsted, 2014).

In accordance with the statutory right for CYPs with medical conditions in the UK to access quality education, these CYPs may access home tuition, on-site HS, school (mainstream/special) with support or PRUs registered to support pupils with medical needs (Farrell and Harris, 2003).

1.1.2. Local Context

Having established the national context of HSs, I will now discuss the local context. At the LA at which I was placed as a Trainee Educational Psychologist (TEP), there are a number of HSs which provide education for CYPs whilst they are in hospital or are unable to attend mainstream school due to their medical needs. There are currently 14 sites situated across the LA, which provide this form of education for CYPs, including hospitals and teaching centres. These HSs deliver education for CYPs with a range of needs, including physical medical needs in addition to mental health needs, such as depression, psychosis, schizophrenia and eating disorders. Several Educational Psychologists (EPs) visit and provide services for the HSs across the LA, and there is not one EP assigned for each site. Although the LA has a number of HSs as detailed, the present research takes place in one HS, which is based on the ward of a large children's hospital.

1.2. Rationale

The rationale for this research paper stems from existing research which indicates that CYPCCs have poorer educational outcomes than their healthy peers. As a TEP, committed to the principles of social justice, this research fulfils a personal and professional obligation to ensure equality of opportunities for all. Maslow et al. (2010) found that although CYPCCs succeed socially (for example, they have similar likelihood of marrying and having children, and report similar levels of romantic relationship quality), they are at increased risk of poorer educational and vocational outcomes compared to healthy peers (for example, they were less likely to graduate from university or be employed, and more likely to receive lower mean income). Stam et al. (2006), who explored the life course of young adults who had grown up with CCs, also found that CYPCCs achieved significantly fewer milestones or were delayed in milestones (regarding autonomy, psychosexual and social development) when compared to peers. Particular CCs, for example childhood cancer, were found to be associated with the biggest delay in achieving milestones. CYPCCs are at an increased risk of being subject to numerous factors which are disadvantageous to their education e.g. substantial school absence⁶ (Closs, 2000) and, overall, CYPCCs are likely to experience higher levels of poverty and personal and social disadvantage than other CYPs (Blackburn et al., 2010). Nevertheless, Dixon (2014) asserts that CYPCCs are overlooked in education.

⁶ Closs (2000) also suggest the following factors which can negatively impact on CYPCCs education: 1. living with uncertainty related to the course of the illness and others' responses to it, 2. having physical and other 'differences' due to the condition and treatment which may cause anxiety or rejection by peers and school staff and 3. requiring medication during the day which can disrupt the school day and socialising opportunities.

The research presented here therefore necessarily address gaps in existing literature regarding CYPCCs, from an educational perspective, explained in Chapter 2. This research aligns with recent legislation, namely Section 100 of the Children and Families Act (2014), which has strengthened the support provided for CYPCCs in schools.

Finally, as an adult with significant experience of hospital, my interest in the topic is as much personal as it is research/professional. This has undoubtedly influenced all aspects of the research.

1.3. Research focus

The present research focuses on CYPCCs' experiences of hospital and HS and aims to address the following research questions (RQs):

- 1. What are the meanings for CYPCCs of their experiences of hospitalisation?*
- 2. What are the meanings for CYPCCs of their experiences of HS?*

1.4. Relevance to Educational Psychologist role

I propose that although the issue of CYPCCs is not necessarily 'mainstream' for the EP role, it is ever more relevant to EP practice (Bunn, 2015). Trends in education – in particular, the inclusion agenda – mean that CYPCCs are increasingly educated in mainstream schools (Bunn, 2015). Thus, it is likely that EPs will encounter this population as part of their work in

schools. Indeed, it was in my role as a TEP that I first became interested in this topic when I was supporting a 6 year old child with sickle cell anaemia. I maintain that this topic (CYPs with medical needs) falls squarely within the remit of the legally mandated duties of EPs, as officers of the LA (DfE, 2013a; DfE, 2014).

1.5. Structure of the study

Following the setting of the research context and rationale for the present research in the current chapter, Chapter 2 reviews relevant existing literature on the topic of CYPCCs. Chapter 3 explains my use of a narrative methodological approach, grounded in a social constructionist stance and interrogates the data collection procedures, ethical considerations and data analysis process. In Chapter 4, I discuss the findings of the study, which I then relate to existing literature in Chapter 5, where implications for practice are also discussed. Chapter 6 concludes the study, evaluating the quality of the research and considering its limitations. Finally, I assess the current research's contribution to knowledge and make suggestions for future research.

2.0. LITERATURE REVIEW

2.1. Chapter overview

The current research focuses on CYPs' perceptions of their experiences of hospital and of schooling in hospital. This literature review takes a 'funnel approach': firstly setting the broad research context, then exploring more specific literature. To this end, the literature review is organised into three broad areas: i) CYPs' experiences of everyday living with chronic medical conditions, ii) CYPs' experiences of hospitalisation; and iii) education for CYPCCs. Crucially, I will review the small body of research into CYPCCs' learning experiences in hospital and also explore literature concerning CYPCCs' experiences of school (reintegration and inclusion) outside of the hospital setting. The voices of CYPCCs are prominent throughout the review, as this is a particular research interest and commitment of mine. As a researcher, this guides the way I consider the literature and the lens through which it is examined.

2.2. Aims and objectives

This literature review aims to provide a comprehensive synthesis of the current knowledge base (theory, policy and research) which exists in relation to CYPs who experience hospitalisation. An important aspect of this review is the critical appraisal of existing knowledge by evaluating the quality of current literature and identifying gaps in the literature (Knopf, 2006; Jesson et al., 2011), to set a context and justification for my research.

2.3. Literature search strategy

Iterative approaches were used to identify literature in a systematic yet flexible manner, allowing further exploration of key themes. To increase transparency, I adopted a systematic approach, as recommended in literature (Hart, 1998; Aveyard, 2010). Inclusion and exclusion criteria (outlined in Table 3) were utilised to select literature to increase replicability and heighten academic rigour, which is important given the subjective nature of iterative approaches to exploring literature (Jesson et al., 2011). However, my influence as a researcher is acknowledged. This review focuses primarily on the experiences of CYPs, the voice of the child and liberation of those under-represented in literature, because these are particular interests of mine, as a researcher. My influence is therefore inevitable with regard to the selection of papers included in this review and my interpretation of them.

Table 3: Inclusion and exclusion criteria adopted in the literature search to identify relevant literature for this review

Inclusion	Exclusion
<ul style="list-style-type: none"> Journal research papers identified as peer-reviewed were selected for inclusion in the literature review. Unpublished doctoral theses were also selected for inclusion, particularly when literature was limited. 	<ul style="list-style-type: none"> Literature focusing on hospital admission relating to: <ul style="list-style-type: none"> mental health of CYPs e.g. psychosis, anorexia nervosa, self-harm and/or psychiatric/mental health hospital settings alcohol/substance use or smoking child abuse (physical or sexual)/neglect adolescent pregnancy 'learning disabilities'
<ul style="list-style-type: none"> Literature with a focus on CYPs' <i>experiences</i> of hospitalisation, rather than other foci such as mortality, immunisation state, emergency department use of young children from low income families, cost of usage by children, 'bravery training' for children, evaluation of (obesity) intervention programmes 	<ul style="list-style-type: none"> Literature focusing on autism/ ADHD/ conduct disorder

Inclusion	Exclusion
<ul style="list-style-type: none"> International literature was included for the purposes of the study, particularly given the scarcity of literature for some areas of the literature review. With regard to legislation, only UK policy and legislative guidance was consulted, given the UK context of the research. 	<ul style="list-style-type: none"> Literature which focused on staff working in children's hospitals, rather than CYPs themselves
<ul style="list-style-type: none"> Literature up to June/July 2015 were included in the study, with no starting date prescribed in the search for literature. 	

Initially, combinations of key words (outlined in Table 4) were used to systematically search for relevant literature through electronic databases such as ProQuest Social Science which provide platforms on which several bibliographic databases can be cross-searched together, e.g. PsychInfo, ERA (Education Research Abstracts) and BEI (British Education Index). Further iterative searches were then carried out in addition to government websites which were accessed for policy and legislative documents.

Table 4: Search terms used to initially identify relevant literature for this review

Subject	Medical intervention	Instruction
Child*	Hospital*	School
Young people	Medical	Learning
Adolescen*		Educat*
<p>Combinations of key word searches involved the use of Boolean operators such as AND (e.g. child* AND hospital*) and OR (e.g. school OR learning). Truncation was also used to identify literature as this considers variations of terminology e.g. adolescen* would reveal literature relating to both 'adolescence' and 'adolescents'.</p> <p>Note: Searches were purposefully kept broad to increase the likelihood of finding suitable literature for the review.</p>		

2.4. CYPs' experiences of living with a chronic condition

Day-to-day experiences of CYPCCs vary considerably, particularly given the varying natures of individual conditions. Literature suggests that CYPCCs are particularly vulnerable to psychological distress, such as anxiety or depressive symptoms (Siegel et al., 1990; Surís et al., 1996; Dantzer et al., 2003; Kakleas et al., 2009) as a direct result of daily living with a chronic medical condition (Rhee et al., 2007). Furthermore, literature indicates that CYPs' social functioning can be impacted by the strains of living with a CC (Seiffge-Krenke and Stemmler, 2003). However, literature appears mixed regarding the extent to which social-emotional wellbeing is impacted upon by chronic illness.

The following section will first explore the emotional wellbeing of CYPCCs, including issues surrounding body image and social functioning, including peer relationships and social participation.

2.4.1. Emotional wellbeing

Table 5 outlines key themes commonly identified in the literature, demonstrating an association between emotional wellbeing and CYPs' experience of chronic illness. CYPCCs' emotional wellbeing is not only important intrinsically, as for all CYPs, but crucially can negatively impact on CYPCCs' health and contribute to the reported deterioration of medical symptoms (Seiffge-Krenke and Stemmler, 2003; Katon et al., 2007).

Table 5: Emotional wellbeing domains which are negatively associated with paediatric illness, as identified in literature

Emotional wellbeing domain	Identifying authors	Views of CYPs sought? (yes/no)
Anxiety Literature suggests that CYPCCs have higher levels of anxiety, although the exact root causes of this anxiety are unclear in the literature.	Dantzer et al. (2003)	No – literature review
Anxiety can be as a result of separation from parents particularly for young children. Anxiety can also arise at the possibility of a painful procedure e.g. injections. Additional anxiety in CYPCCs is due to falling behind with their usual routines and activities e.g. CYPCCs expressed sadness and anxiety about missing out on the following: school, opportunities to socialise with their friends and family life, including interactions with their parents and siblings.	Rokach and Parvini (2001)	No – literature review
There is an association between parent-reported psychological distress and adolescent-reported anxiety in adolescents with CCs.	Lopez et al. (2008)	Yes – questionnaires. Parents were also participants.
Anxiety and psychological distress more generally can manifest itself in different ways for CYPCCs, for example school phobia and separation anxiety. Anxiety in CYPCCs vary, and can be associated with the type of illness a CYP experiences. Neville (1996) found that participants with leukaemia had significantly higher levels of anxiety than other illness categories.	Neville (1996)	Yes – questionnaires
Anxiety in relation to initiating contact with peers (peer relationships).	Wilson et al. (2007)	Yes – qualitative interviews
Depressive symptoms Literature suggests that CYPCCs have higher levels of depressive symptoms than other CYPs.	Dantzer et al. (2003) Siegel et al. (1990)	No – literature review Yes – questionnaires and checklists
Adolescents with diabetes are at an increased risk of developing eating disorders, depressive symptoms and substance abuse. These can lead to non-compliance with treatment and decline of their diabetic management. Female adolescents who have family problems and concurrent psychiatric difficulties are more likely to experience depressive symptoms.	Kakleas et al. (2009)	No – literature review

Emotional wellbeing domain	Identifying authors	Views of CYPs sought? (yes/no)
A significantly higher number of females with CCs reported emotional problems, feeling in a bad mood, feeling unhappy, believing nothing pleased them, having suicidal thoughts and conveying depressive symptomatology, when compared with controls.	Surís et al. (1996)	Yes – questionnaires
CYPCCs have more depressive symptoms because they are more isolated socially.	Blum (1992)	No – literature review
CYPs with cancer who have poorer body image have greater anxiety levels, depression and behavioural problems. They also have compromised emotional and social quality of life, relating to their health.	Fan and Eiser (2009)	No – literature review
Some evidence indicates that the psychological and psychosocial functioning of people with cystic fibrosis is similar to that of people without the illness, until the disease becomes more severe. However some evidence also suggests that patients with cystic fibrosis do suffer an increased likelihood of psychiatric problems e.g. depression.	Pfeffer et al. (2003)	No – literature review
Self-esteem Literature suggests that CYPCCs are at an increased risk of having lower self-esteem.	Siegel et al. (1990)	Yes – questionnaires and checklists
In this study, CYPs with epilepsy had lower self-esteem than CYPs with diabetes, demonstrating that the impact on self-esteem may vary depending on the CC a CYP experiences. There is an association between low self-esteem and behavioural difficulties in CYPCCs.	Hoare and Mann (1994)	Yes – questionnaires
The study identifies that medical procedures, fear of dying and low self-esteem were the chief stressors that affect the wellbeing of CYPs diagnosed with cancer.	McCaffrey (2006)	Yes – focus group discussions with CYPCCs. Parents and hospital professionals were also participants in the study.
CYPs' own perceptions of the impact of disability are integral to self-esteem (i.e. CYPCCs perceiving a greater impact of the disability report lower self-esteem) as opposed to physician–assessed severity/functional variables.	Manuel et al. (2003)	Yes – questionnaires

Emotional wellbeing domain	Identifying authors	Views of CYPs sought? (yes/no)
Changes in body image may have adverse effects on self-esteem.	Fan and Eiser (2009)	No – literature review
Feelings of loss CYPCCs experience a perception of loss, in the sense of ‘ missing out ’ e.g. having to give up sporting/social activities as a result of their medical condition. This missing out can be associated with feelings of sadness, frustration and/or unfairness.	Rhee et al. (2007) Wilson et al. (2007)	Yes – focus group interviews with adolescents Yes – qualitative interviews
Loss of control can be a major stressor for CYPCCs.	McCaffrey (2006)	Yes- focus groups with CYPCCs. Parents and hospital professionals were also participants in the study.
CYPCCs can report feelings of ‘being lost’ regarding changes in their body and not being the same anymore, e.g. feeling weak and tired and being trapped in a ‘sick body’. CYPCCs also report feeling ‘lost’ in relation to feelings. That is to say feeling that their psychological defences are weakened as a result of managing their condition and feelings of sadness and difficulties coping.	Forsner et al. (2005)	Yes – interviews
Feelings of ‘pain/hurt’ CYPCCs experience emotional pain in relation to distress/suffering regarding the effects of their illness on daily life. Emotional pain is also related to CYPCCs not being able to do all that they wanted to, leading to feelings of difference.	Woodgate (1998)	Yes – interviews
CYPCCs may experience physical pain/hurt , e.g. discomforting sensations, pain, dizziness and nausea. These feelings of physical pain can be frightening and overwhelming for CYPCCs. CYPCCs may feel hurt by others . That is to say, CYPCCs may experience feelings of loneliness and feelings that only they can experience their illness-related life experience and others (e.g. parents) could never truly understand.	Forsner et al. (2005)	Yes – interviews

Table 5 demonstrates the variation regarding types of investigative approach to exploring CYPCCs' emotional wellbeing. A number of studies, for example, use a literature review approach (e.g. Blum, 1992; Rokach and Parvini, 2001; Dantzer et al., 2003; Pfeffer et al., 2003, Kakleas et al., 2009), rather than direct research with CYPCCs, in order to create a synthesis of existing knowledge. Similarly, Surís et al. (1996) adopted a methodological approach which involved comparing two groups extracted from the Barcelona Adolescent Health Survey, namely CYPCCs (n = 162) and CYPs without CCs (n = 865) regarding their emotional wellbeing, and applying statistical tests to facilitate interpretation of questionnaire data. Although this is a time-effective way of analysing many data, for example not meeting face-to-face with hundreds of CYPs, conducting research from a distance like this is likely to impact on the interpretation of outcomes, with a less in-depth and contextually-rich approach. In Surís et al.'s (1996) study, for example, the researchers did not have access to important information about participants such as the severity, course or prognosis of CCs which are likely to be factors which impact on CYPCCs' emotional wellbeing. Likewise, Rhee et al. (2007), although the researchers adopted an interview approach with adolescents to explore their experiences of asthma, did not collect vital information concerning illness severity or medication usage, which may have impacted their findings regarding the positive outlook and utility of chronic illness.

Table 5 does not depict the entire picture however. Firstly, there is the argument that vulnerability to emotional distress is dependent on the nature of the particular condition (Hoare and Mann, 1994; Neville, 1996), although this is disputed (Surís et al., 1996), treatment (Abrams et al., 2007) and illness severity (Seiffge-Krenke and Stemmler, 2003).

Secondly, although it appears that CYPCCs are more vulnerable to psychological distress, there are factors which can protect against this outcome, such as social support (Schroevers et al., 2003).

Moreover, evidence suggests that CYPCCs appear as psychologically well-functioning (Pfeffer et al., 2003; Szyndler et al., 2005) and there is minimal difference between CYPCCs and CYPs without CCs, with regard to self-esteem (Neville, 1996; Ritchie, 2001; Manuel et al., 2003), anxiety and depression (Abrams et al., 2007). Rhee et al. (2007) also point out that CYPs can view their chronic illness positively, for example seeing it as helpful in providing an excuse to exclude themselves from undesirable situations, such as physical activities or smoking/drinking.

Research literature also suggests that CYPCCs experience a number of additional worries resulting from their conditions, such as worries about their future health (Cappelli et al., 1989), practical difficulties (Rhee et al., 2007; Wilson et al., 2007), treatment burden (McCaffrey, 2006; Hegarty et al., 2008), emotional challenges associated with disclosure concerning their condition (Wilson et al., 2007), relapses, developing health complications, fears of dying soon, social isolation, school and future career choices (Wolman et al., 1994; Woodgate, 1998; McCaffrey, 2006). Havermans and De Boeck (2007) emphasise the difficulties for CYPCCs of constantly balancing being ill with living like healthy children. Furthermore, D'Auria et al. (2000) found that CYPCCs with cystic fibrosis recalled their

internal struggles of understanding the significance and relentless and lifelong nature of their condition, its symptoms, its management and its shifting course.

2.4.1.1. Body image

In addition, a large body of literature focuses on the issue of CYPCCs' body image⁷. CYPCCs are reported to have less positive body image than samples of healthy controls (Wolman et al., 1994; Pinquart, 2013), although the consistency of this evidence is disputed (Fan and Eiser, 2009). CYPCCs' purported difficulties concerning body image may stem from physical changes, such as hair loss, weight changes and surgical scars, which create a sense of not feeling 'normal' (Abrams et al., 2007). Additionally, literature indicates that the onset of pubertal maturation can be either brought forward or postponed in CYPCCs, which can lead to a sense of difference and can negatively impact CYPCCs' body image and emotional wellbeing (Blum, 1992; Sawyer et al., 1995). However, the association between CYPCCs and negative body image does not appear strong and other factors impact on these findings being reported in literature, such as the nature and duration of the condition, age of CYP, gender, stage of illness, psychological adjustment and study characteristics (Yan et al., 1999; Hegarty et al., 2008; Fan and Eiser, 2009; Pinquart, 2013).

⁷ Body image relates to a multifaceted construct that involves self-perceptions and self-attitudes related to the body, which includes thoughts, beliefs, feelings and behaviours (Cash, 2004).

2.4.1.2. Systemic factors

Evidence suggests that the wider systems around CYPCCs, particularly the family, have a significant impact on the emotional wellbeing of CYPCCs (Bunn, 2015). Although families are not the primary focus of this research, literature suggests the existence of an important reciprocal relationship between the emotional wellbeing of CYPCCs and family factors. Firstly, considering that a CYPCC's diagnosis is regarded as a 'life-shattering' and devastating experience, which requires considerable life adjustments and changes to the family's sense of 'normal' (Carpenter and Narsavage, 2004), it is unsurprising that a child's health and wellbeing impacts on their family. Bunn (2015) depicts an intense emotional journey for parents of CYPCCs, supported by Granek et al. (2014), whilst the additional strains of living with a paediatric CC are suggested to contribute to family conflicts and problematic parent-child relationships (Kakleas et al., 2009). Importantly, the family's response to the condition has an impact on the CYPCC (Knafl et al., 1996; Pfeffer et al., 2003).

Literature suggests that parents of CYPCCs can be more overprotective, which is negatively associated with CYPCCs' wellbeing, for example decreased self-esteem and higher anxiety levels (Blum, 1992; Manuel et al., 2003). Furthermore, parental psychological distress and perceived child vulnerability are reported to significantly predict adolescent anxiety, with perceived child vulnerability appearing to be a possible mechanism by which parental psychological distress influences anxiety in CYPCCs (Lopez et al., 2008). However, it is to be noted that in Lopez et al.'s study illness severity was unaccounted for, which is significant given that illness severity could affect parental or adolescent distress and CYPCCs' perceived vulnerability.

Capelli et al. (1989) suggests that CYPCCs worry about the impact of their illness on family members and are concerned about family members' responses to their illness and perceived additional stress for the family. It is suggested that CYPCCs' elevated emotional wellbeing is connected with higher levels of family connectedness and cohesion (Wolman et al., 1994; Szyndler et al., 2005; Piazza-Waggoner, et al., 2006). Remarkably, family connectedness is said to have a greater impact on CYPCCs' wellbeing than the CC itself (Wolman et al., 1994).

In summary, there appears to be an association between paediatric chronic illness and aspects of emotional wellbeing, such as self-esteem, depressive symptoms, anxiety, feelings of loss and body image. However, the association is far from conclusive, in terms of the inevitability of poorer psychological wellbeing for CYPCCs, but rather appears to be linked to certain circumstances which increase the likelihood of poorer emotional outcomes, such as family disharmony.

2.4.2. Social issues

CYPCCs may experience difficulties with social relationships (Pfeffer et al., 2003), which is significant given that adolescence is a time in which developing friendships and feeling part of a recognised peer group is of great importance (Reis and Youniss, 2004; Zimmerman, 2004; Shepherd, 2014). CYPCCs can feel a sense of difference to their healthy, unaffected peers (Christian and D'Auria, 1997; Rhee et al., 2007). Furthermore, CYPCCs consider relationships as an area of importance (Wilson et al., 2007) and is a source of stress and

concern for them (Seiffge-Krenke and Stemmler, 2003). Christian and D'Auria (1997) purport that CYPCCs struggle to disclose their condition to peers, due to uncertainties of the meaning(s) of their diagnostic label for others and concerns about negative reactions of peers as a result of the disclosure.

Research literature indicates that CYPCCs may experience social difficulties as a secondary impact of their CC, for example the effect of changes in physical appearance on peer relationships (Spirito et al., 1991). Significantly, difficulties with peer relationships arise from restrictions relating to physical and/or social activities, as a result of physiological changes and adaptations made to the level and nature of their participation (Spirito et al., 1991; D'Auria et al., 2000; Meijer et al., 2002). Spirito et al. (1991) argue that medical conditions influence peer relations in different ways, which is further supported by the assertion that illness severity can also impact on how CYPCCs perceive difficulties in peer relations (Seiffge-Krenke and Stemmler, 2003). Hospitalisation and clinic visits may further contribute to feelings of disconnectedness with peer groups at school, which can lead to social isolation and reduced opportunities to feel socially competent (Blum, 1992; D'Auria et al., 2000). Conversely, Meijer et al. (2002) found that the presence of CCs did not negatively impact on social skills in CYPCCs, as in their study girls displayed positive assertive social skills with their peers and boys demonstrated lower scores for inadequate social skills than healthy norms. However, it is noted that Meijer et al. used self-report questionnaires involving hypothetical reactions, and therefore discrepancies may exist between CYPCCs' recounted hypothetical reactions and their genuine reactions in real-life situations.

Cross-cultural research indicates that CYPCCs are considerably more likely to report that they have been victims of bullying compared with students without CCs (Sentenac et al., 2011). A substantial additional risk of being bullied (30%) was found when CYPs reported both a CC or disability and restriction in school participation (Sentenac et al., 2011).

Peers are an important source of support for CYPCCs (Christian and D'Auria, 1997; Ritchie, 2001), in particular when protecting against bullying at school and with 'covering up' when required (Wilson et al., 2007). Principally, peers with CCs are regarded as a particularly vital resource for CYPCCs. Hospitalisation is an opportunity for interacting with other CYPs with similar medical conditions and illness-related life experiences, with whom they feel they can be understood and have a sense of equality (Christian and D'Auria; 1997; D'Auria et al., 2000). This is important for identity formation (D'Auria et al., 2000).

2.4.3. Coping with everyday challenges

Friendship has been identified as one source of coping (Section 2.4.2): in this section I review other coping strategies used by CYPCCs in the face of daily challenges associated with CCs. The coping styles of CYPCCs have important implications for their quality of life (Pfeffer et al., 2003) and are vitally important as the psychological needs of some CYPCCs are often missed (Kahalley et al., 2013).

'Coping' is defined as a person's "efforts to manage... the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (Folkman et al., 1986, p. 572). Much of the emphasis concerning CYPCCs' illness-related coping focuses on CYPCCs' need to live their lives as 'normally' as possible (Ferguson and Walker, 2014). Carpenter and Narsavage (2004) highlight the lifestyle adjustments families take to ensure a sense of normalcy for CYPCCs, whilst Rhee et al. (2007) indicate the 'toughness' of CYPCCs motivated by their desire to keep up with healthy peers. However, this sometimes compromises effective self-management of their condition, which is argued to be an important aspect of coping for people who live with CCs (De Ridder et al., 2008).

Christian and D'Auria (1997) propose two dimensions of maintaining normalcy for CYPCCs: 'keeping secrets' and 'hiding visible differences'. In this study, adolescents reported that they concealed information about their condition to avoid negative responses from others. Furthermore, CYPCCs reported their attempts to hide visible differences from peers, such as the 'cystic fibrosis cough' and taking medication in front of others, which enabled them to decrease peer comparisons and avoid peer rejection. Wilson et al. (2007) argue that central to CYPCCs living as normal lives as possible, is a strong determination not to allow illness to stop them from doing anything, even if this entails additional planning and effort to engage in activities similar to their peers.

A body of literature indicates the significant role of optimism, positivity and hope in CYPCCs' coping strategies. CYPCCs employ the strategy of optimism, maintaining a positive outlook

on life and focusing on the positive outcomes of illness, which is integral to coping with everyday challenges (D'Auria et al., 2000; De Ridder et al., 2008; Ferguson and Walker, 2014). Furthermore, Lynch et al. (2007) found that adolescents in particular, adopt the cognitive strategy of positive self-talk, for example instructing themselves not to worry about pain.

It is also suggested that CYPCCs adopt other coping strategies as outlined in Table 6. However, evidence for these strategies in literature is limited and further research is needed to provide additional support for these specific coping strategies.

Table 6: Coping strategies employed by CYPCCs to manage daily illness-related challenges, as indicated by literature

Identifying authors	Research design	Sample	Coping strategies
Ferguson and Walker (2014)	Qualitative, longitudinal case study. Method of data collection was interviews.	31 adolescents in Australia	<ul style="list-style-type: none"> ○ Having clear aims and goals for the future. Such aspirations improved motivation to overcome short-term difficulties and impacted on CYPCCs' feelings of empowerment and control in their lives. ○ Remaining connected with school and friends.
De Ridder et al. (2008)	Literature review	N/A	<ul style="list-style-type: none"> ○ Remaining as active as possible ○ Emotional regulation – acknowledgement and expression of their (negative) emotions in order to take control of their lives.
Christian and D'Auria (1997)	Qualitative study using grounded theory. Retrospective interviews were adopted.	20 adolescents (11-18 years) each with a diagnosis of cystic fibrosis	<ul style="list-style-type: none"> ○ Discovering a new baseline – adolescents came to the realisation that comparing themselves with healthy peers was unhelpful. Discovering a new baseline was critical in enabling

Identifying authors	Research design	Sample	Coping strategies
			<p>adolescents to successfully reduce feelings of difference in their lives.</p> <ul style="list-style-type: none"> ○ This is supported by Rhee et al. (2007) who found that a 'modifying' coping style led adolescents to appear content with their lives and perceive some control over their illness.
Lynch et al. (2007)	A variety of questionnaires were used in the study, for example the Pain Coping Questionnaire.	272 children (8-12 years) and adolescents (13-18 years) who presented at a paediatric chronic pain clinic	<ul style="list-style-type: none"> ○ Behavioural distraction – this study found that boys of all ages were more likely to do something active or enjoyable to take their minds of their situation. ○ McCaffrey (2006) also found that many children use distraction techniques, for example watching TV, in order to cope. ○ Lynch et al.'s study highlights sex and age based preferences in coping strategies e.g. girls preferring to engage in social support to cope whilst boys tend to opt for behavioural distraction.
Wilson et al. (2007)	Qualitative study which utilised interviews	16 young people (16-21 years)	<ul style="list-style-type: none"> ○ Humour was used by young people to obscure difficulties/ differences that were noted or in response to questions they were reluctant to answer.
McCaffrey (2006)	In-depth exploratory study. Focus groups and individual interviews with CYPs, their parents, and hospital staff.	Children diagnosed with cancer (n = 6), their parents (n = 6) and hospital professionals (n = 23)	<ul style="list-style-type: none"> ○ Home cooking ○ Painting ○ Hats to cover their bald heads ○ Music ○ Massages
Rhee et al. (2007)	6 focus group interviews were conducted	19 adolescents aged 12 – 18 years diagnosed with asthma in USA	<ul style="list-style-type: none"> ○ 'Guardedness' – adolescents were overly vigilant and displayed potentially exaggerated behaviours that appeared to be rooted in fear of potential

Identifying authors	Research design	Sample	Coping strategies
			dangers of asthma symptoms
Meijer et al. (2002)	Measures were used relating to social adjustment, self-esteem and behaviour difficulties. Brief interviews with parents were also conducted.	84 adolescents (13 -16 years) diagnosed with a CC	<ul style="list-style-type: none"> ○ Coping style of 'confrontation' which was characterised by active and purposeful problem-solving is an effective behavioural coping style for CYPCCs. In the study, this was reflected by a high social self-esteem, the use of suitable social skills, and to a lesser degree, the absence of anxiety in social situations and the use of assertive behaviour.

From Table 6 above, it is interesting to note the vast range of coping strategies employed by CYPCCs in the face of daily challenges as a result of their CCs. However, as outlined in Table 6, the studies vary considerably in their research design and methodological implications. The research conducted by Meijer et al. (2002) and Lynch et al. (2007), for example, involves the use of questionnaires on a large scale (n = 84 and n = 272 respectively). Although a great deal of information is gathered via conducting questionnaires with a large sample size, this study was unable to capture in-depth information about individual personal experience. Similarly, there are inevitable differences in the information co-constructed in focus groups (as in Rhee et al.'s 2007 and McCaffrey's 2006 studies) versus individual interviews (e.g. Wilson et al., 2007) as a result of factors such as group dynamics. Additionally, the studies vary in terms of participant population, for example some studies focused on an older and narrower age range of CYPs, such as Wilson et al. (2007), whose participants were aged 16 – 21 years, and some studies focus on a wider (and lower) age range such as Lynch et al. (2007), whose participants were aged from 8 years. Furthermore, the participant population also varies between studies because the context and focus of the research differs in each.

Lynch et al. (2007), for example, focus specifically on CYPCCs' coping with chronic pain whilst Wilson et al. (2007) focused on the coping experiences of CYPCCs with a particular bladder condition.

Despite the lack of supporting research into the coping strategies identified in Table 6, these findings are interesting and significant. Findings that suggest coping strategies such as adolescents' attempts to employ adjusted expectations for their lives (Christian and D'Auria, 1997) and the importance of having clear aspirations for their lives (Ferguson and Walker, 2014) have significant value. The research designs and epistemological foundations of these studies meant that interviews were conducted with CYPCCs and the findings are based on their responses and highlight the value of research into CYPCCs' own perspectives on their daily experiences and coping.

It is argued that the buffer effects of psychosocial resources are different, depending on the type of CC experienced (Bisschop et al., 2004). Additionally, Piazza-Waggoner et al. (2008) found that CYPs with mild illness severity reported less adaptive coping, contrary to their hypothesis, compared to more severe illness and no illness groups. CYPCCs with milder illness cope less well than others possibly because they perceive their illness as being intermittent, acute episodes rather than a continuum of ill-health. This further highlights individuality of CYPCCs' experiences and perceptions and the need for research epistemologies to respect and enable this.

2.4.4. Summary

In summary, the literature reviewed so far indicates that CYPCCs may be at an increased risk of emotional and social difficulties, as a result of their CCs, although there is also substantial evidence to the contrary. Nevertheless, the literature suggests that CYPCCs are a ‘resilient’ population, characterised by the range of coping strategies they employ to overcome day-to-day challenges. Throughout the literature on the daily experiences of CYPCCs, I have been surprised at how rarely CYPCCs are actually consulted with regard to their own day-to-day life experiences. Although many researchers opt for gaining CYPs’ views via questionnaires (e.g. Hoare and Mann, 1994; Neville, 1996; Lynch et al., 2007; Piazza-Waggoner et al., 2008), which is not erroneous, there is a distinct lack of research in this area which seeks *in-depth* data from CYPCCs themselves.

2.5. Experiences of hospitalisation

In Section 2.4 I considered CYPCCs’ everyday experiences of living with a CC. In this section I explore literature relating to CYPCCs’ experiences whilst in hospital, which is key to CYPCCs’ illness-related experiences.

2.5.1. Hospital environment

With regard to CYPCCs’ experience of hospitalisation, a large proportion of research focuses on CYPs’ preferences relating to the hospital environment, including the physical environment (décor, design, facilities etc.) and the social environment (pertaining to

interactions with people), which is based on the assumed relationship between environment and emotional wellbeing. Research into CYPs' preferences for the hospital environment includes participants with varying degrees of hospital experience, but studies consistently demonstrate no significant differences between the preferences of hospitalised and non-hospitalised CYPs (Ullán et al., 2012) and CYPs with and without overnight hospital experience (Blumberg and Devlin, 2006).

2.5.1.1. Physical environment

Unsurprisingly, literature indicates that CYPs' preferences for the physical hospital environment vary according to their age. Aldiss et al. (2009) suggest that young children aged 4-5 years old particularly identify toys, the playroom and activities as the most important features of hospital for them, which are considered important for coping with illness and the associated emotions (Garipey and Howe, 2003), as well as overcoming boredom, elevating choice and control, and lessening isolation through increased socialisation (Lambert et al., 2014a).

For adolescents, the literature suggests a need for facilities which cater specifically for their age group (Boswell et al., 2000; Battrick and Glasper, 2004; Coyne and Kirwan, 2012). A distinct need for privacy is apparent for adolescents, for example during physical examinations and when dressing (Boswell et al., 2000; Battrick and Glasper, 2004; Blumberg and Devlin, 2006; Lambert et al., 2014b). Adolescents prefer to be accommodated together

with CYPs of a similar age (Boswell et al., 2000), a recommendation from ‘Youth Matters’⁸ (Viner and Keane, 1998).

Research suggests that a ‘home away from home’ and familiarity are important to CYPCCs regarding the physical hospital environment. Personalisation of CYPCCs’ hospital areas is vital, for example with posters, teddy bears and photographs from home (Boswell et al., 2000; Lambert et al., 2014b) and accessory items, such as cushions and rugs (Coad and Coad, 2008). CYPs prefer to have a colourful physical environment (Boswell et al., 2000; Koller and McLaren, 2014; Lambert et al., 2014b), although Blumberg and Devlin (2006) caution that despite adolescents’ preference for the cheerful bright colours associated with childhood, they reject symbols associated with childhood, such as balloons and teddy bears. However this study is limited due to the homogeneity of the sample and that participants were aged 12-14 years which is not necessarily representative of the adolescence period. Ullán et al.’s (2012) study supports adolescents’ requirement for a non-childlike environment.

Additionally, literature indicates CYPs’ preference for nature and water thematic designs and textures which incorporate metal, glitter or shine (Coad and Coad, 2008). Although Whitehouse et al. (2001) indicate the potential benefits of a hospital garden for restoration and therapeutic healing, the study is unlikely to represent hospitalised CYPs’ needs as few

⁸ ‘Youth Matters’ makes a designated adolescent unit desirable due to adolescents’ dissimilar psychosocial and developmental needs compared with younger children and adults. A separate unit however is not always possible in reality and not always desired by CYPs (Boswell et al., 2000; Blumberg and Devlin, 2006).

hospitalised CYPs were observed in the garden, but rather healthy siblings, outpatients and adults.

Literature highlights CYPs' ability to conceptualise space on a profound and analytic level, not only being able to think about the physical environment in terms of meeting their needs but also how it makes them feel emotionally (Koller and McLaren, 2014). Likewise, Ullán et al. (2012) indicate the sophistication of adolescents' perspectives regarding hospital design, with CYPs' preferences demonstrating increased sensitivity to dimensions and nuances of hospital design (the needs, experiences and emotions of hospital users) compared to adults in the study, who focused more on the physical aspects of the setting.

2.5.1.2. Social environment

Research findings about CYPs' perceptions of their interactions with nurses and doctors are mixed (Carney et al., 2003; Board, 2005; Yates et al., 2009; Coyne and Kirwan, 2012). Furthermore, Jensen et al. (2012) indicate that CYPs do not differentiate between professionals and young children view hospital staff as secondary to their parents (Aldiss et al., 2009). Shepherd (2014) highlights the unique interactions between young nursing students and adolescents, which provide CYPCCs with a sense of normalcy, socialisation opportunities and boredom relief. Other staff in hospital can also be important in a CYP's social environment, for example clowns (Linge, 2012) and youth workers (Yates et al., 2009).

The literature indicates that parents are integral to the social environment for hospitalised CYPCCs, for both young children (Aldiss et al., 2009; Lambert et al., 2014b) and older children (Carney et al., 2003). Moreover, CYPCCs report that they enjoy the time spent with their parents in hospital and enjoy the increased attention they receive (Jensen et al., 2012). However, although it is now generally accepted that parents are a vital part of hospitalised CYPCCs' social environment in hospital, this has not always been the case. The seminal work of Bowlby and Robertson in the 1950s and their missionary style campaigning significantly influenced the practice of how CYPs were cared for in hospital and was a catalyst for changes in health care systems globally (Aslop-Shields and Mohay, 2001). Bowlby's research findings during the 1950s (for example Bowlby, 1951) were supported by Robertson's films, 'A Two-Year-Old Goes to Hospital' (1952) and 'Going to Hospital with Mother' (1958). These films highlighted the potential emotional distress for young children as a result of parental separation during hospital stays (Bowlby and Robertson, 1952) and the benefits of parental presence during hospitalisation (Robertson, 1958). Van der Horst and Van der Veer (2009) argue that although Bowlby and Robertson were significant in influencing societal changes in terms of legislation and practice concerning the care of hospitalised CYPs, they were not the only contributors to these changes. The authors argue that a number of other factors, such as parental pressure groups and concerned doctors, were also influential to changes in practice and legislation regarding CYPs in hospital (Van der Horst and Van der Veer, 2009).

As discussed throughout Section 2.4.2, during hospitalisation, peers are a primary aspect of the social environment for CYPCCs (Christian and D'Auria, 1997; D'Auria et al., 2000; Carney et al., 2003).

2.5.2. Involvement in consultation and decision-making

CYPs' involvement in consultation about their own healthcare is a predominant theme in literature about CYPs' experience of hospital. Policy indicates that medical services should be child-centred and that CYPs should be included in all elements of their healthcare (DoH, 2003). However, the literature suggests that although hospitalised CYPs should be and want to be involved as partners in consultation and decision-making regarding their healthcare, this is not often executed in practice (Coyne, 2006; Van Staa, 2011; Wechter, 2014).

Van Staa's (2011) research found that adolescents often acted as 'bystanders', rather than 'main characters' because their participation was neither requested nor encouraged. This is supported by Coyne (2008) who indicates that CYPs often occupy a marginalised position and are passive in decision-making processes in hospital. How CYPs are regarded by adults (parents and hospital staff) is a further barrier to CYPs' involvement in consultation about their care. CYPs are positioned in a context of an unequal power relationship and where adults often make decisions 'in the child's best interests', rather than actively involving the CYP themselves (Bricher, 2000). Parents and healthcare professionals have reservations about involving CYPs in decisions about their care for many reasons such as uncertainty about competency, lack of time and protective attitudes (Bricher, 2000; Coyne, 2008). Jolley (2006) argues that nurses should consider CYPs' views with more gravity, even when the CYP disagrees with the prescribed care or treatment.

Furthermore, there are deficient skills in meeting CYPs' communication needs, which is imperative if CYPs are to be meaningfully included in consultation. Lambert et al. (2012) propose that CYPs need to be consulted regarding their preferences for information (e.g. format, quantity and delivered by whom). Furthermore, Coyne and Kirwan (2012) propose that CYPs struggle to access the information that is given to them by medical professionals and would prefer information to be given through the use of shorter sentences and child-friendly language. Although this study found that CYPs' wishes mainly centred around the need for greater information and involvement in communication with healthcare professionals, the data is likely to have been influenced by the interview questions, which focused on information-sharing and decision-making. Therefore, CYPs may have included these issues in their wishes, which they may not otherwise have prioritised.

Bricher (2000) proposes that excluding CYPs from involvement in decision-making about their care is to deny them their rights at a time of particular vulnerability and powerlessness. Noyes (2000) indicates that ventilator-dependent CYPs were discriminated against and excluded from making important decisions. Furthermore, these CYPs were frequently denied education whilst in hospital and almost all participants in the study spent prolonged periods of time in hospital, when they no longer wanted or needed to be there.

Evidence suggests that CYPCCs' involvement in their care is vital to enhancing wellbeing: when CYPs' need for participation is overlooked, they can feel sad, ignored and rejected (Coyne and Kirwan, 2012). Furthermore hospitalised CYPs require information and

involvement in order to feel prepared for procedures (Coyne and Kirwan, 2012). Moreover, adolescents need to be facilitated to take the lead in communications in preparation for transition to adult healthcare (Van Staa, 2011).

2.5.3. Emotional and physical wellbeing in hospital

This section explores literature in relation to the emotional and physical wellbeing of CYPPCs in the hospital context specifically, rather than more generally in day-to-day life. Literature suggests that hospitalised CYPs experience a range of emotions, sometimes contrasting, such as relief, happiness, anxiety, uncertainty, frustration, loneliness, guilt and anger (Boyd and Hunsberger, 1998; Salmela et al., 2010; Wilson et al., 2010; Ford, 2011) which are changeable, even over short periods (Savedra and Tesler, 1981; Boyd and Hunsberger, 1998). This range of emotions is indicative of positive as well as negative experiences in hospital for CYPs (Carney et al., 2003; Wilson et al., 2010; Jensen et al., 2012).

However, research findings indicate that CYPs' quality of life is lower in hospital (than at home) and as an inpatient (than as an outpatient), (Hegarty et al., 2008; Speyer et al., 2009). Furthermore, hospitalisation not only impacts on CYPs' wellbeing whilst in hospital, but negative outcomes may follow including internalising and externalising behaviours (Small and Melnyk, 2006) and even PTSD symptoms (Raby and Edwards, 2011).

From a theoretical position, CYPs vary remarkably with their psychosocial responses to hospitalisation. Vessey's (2003) model utilises a developmental framework and identifies important inter-relating variables which affect a child's psychosocial response to hospitalisation, such as: age, length of hospitalisation, hospital milieu, type and severity of illness, symptomatology, previous adaptive capacity, parent-child relationships and parental equilibrium. Furthermore, caution must be exercised when interpreting literature on hospitalised CYPs' wellbeing as parents tend to give lower estimates of their children's health-related quality of life than the CYP themselves (Speyer et al., 2009).

Relating to CYPs' emotional wellbeing in hospital, literature emphasises the need for CYPs to maintain a connection with home, particularly as CYPs miss home when they are in hospital, including parents, siblings and the home environment, for example their bed and TV (Aldiss et al., 2009). Furthermore, hospitalised CYPs want to go home (Carney et al., 2003) and the ultimate relief for them indeed, is going home (Wechter, 2014). In order to remain connected to home, CYPs transfer their everyday life to hospital settings, for example taking part in leisure activities as they would at home (Jensen et al., 2012) and personalising their hospital space, with features from home (Boswell et al., 2000; Lambert et al., 2014b).

Evidence suggests fear is a predominant emotion experienced by hospitalised CYPs (Wilson et al., 2010), as medical care is conceptualised by CYPs as 'being threatened by a monster' (Forsner et al., 2009). Table 7 below summarises the research into hospital-related fears experienced by CYPs.

Table 7: CYPs' hospital-related fears as depicted in literature

Identifying authors	Hospital-related fears
Salmela et al. (2010)	<ul style="list-style-type: none"> ○ Nursing (medical) interventions and the possibility of pain ○ Separation from parents ○ Lack of information ○ Medical instruments and equipment ○ Helplessness
Pölkki et al. (1999)	<ul style="list-style-type: none"> ○ Fear associated particularly with needles:- <ul style="list-style-type: none"> ○ Feeling of fear caused by the appearance of a needle; ○ The piercing of the skin with the needle; ○ The intensity of the pain; ○ The CYP's ability to anticipate the painful event beforehand
Coyne (2006)	<ul style="list-style-type: none"> ○ Separation from parents and family ○ Interruption to family routines and everyday activities ○ An unfamiliar environment with implications relating to fears of the unknown and professionals ○ Investigations and treatments – operations, needles, mistakes in treatment, harm to body, mutilation, pain, altering body image and dying. ○ Loss of self-determination including loss of independence. Also, lack of control concerning the following: personal needs, sleeping and waking times, food/mealtimes and timings of procedures.

Table 7 demonstrates the strong association between emotional and physical wellbeing for hospitalised CYPs. CYPs experience more negative emotion during blood drawing and following surgery (Savendra and Tesler, 1981) and IVs⁹ and invasive procedures are key stressors for hospitalised CYPs (Boyd and Hunsberger, 1998). Furthermore, Rokach and Parvini (2011) highlight that the prospect of pain is anxiety-provoking for CYPs, as unlike adults, they associate pain with disfigurement and/or punishment. The negative impact on emotional wellbeing induced by the prospect of painful procedures is significant as fear increases physiological feelings of pain (Pölkki et al., 1999). Conversely, Jensen et al. (2012)

⁹ IVs are thin bendable tubes that are inserted into the veins for the purpose of transferring fluids, medicines or blood to the patient.

found that despite CYPs' negative thoughts about the possibility of pain associated with needles, CYPs reported that the medical procedure was painless.

Research suggests that pain is central to CYPs' physical wellbeing whilst in hospital. Twycross and Collis (2013) indicate that 58% of CYPs in their study experienced intense pain and 24% moderate pain. Furthermore, Sermet-Gaudelus et al. (2009) argue that although pain is more intense and longer for adults, there is no significant difference between the rate and recurrence of pain between CYPs and adults. Thus, pain is key to the experience of hospitalised CYPCCs, despite claims of a high incidence of untreated pain, especially for CYPs with cystic fibrosis (Sermet-Gaudelus et al., 2009). Pölkki et al. (1999) propose that needles in particular cause physiological pain to CYPs relating to procedures concerning bone marrow, the spinal cord, veins and with muscle and sub-cutaneous tissue. The authors report that painful feelings such as poking, stinging and aching are associated both prior to and subsequently following the procedure.

However, feelings of physiological pain may differ in CYPs according to their 'health anxiety', (with more 'health anxious' CYPs likely to experience heightened feelings of pain; Hadjistavropoulos et al., 1998), and pre-hospital factors, such as previous surgery (Franck et al., 2004).

2.5.4. Coping in hospital

CYPCCs' coping is an important theme in their everyday experiences (discussed in Section 2.4.3) and the literature suggests that coping during hospital visits and/or stays is vital to

CYPCCs' physical and psychological wellbeing. Although hospital can be a trying experience, it is suggested that CYPs are resilient and are able to adapt to the hospital environment. Hospitalised CYPs become adept at identifying and implementing a repertoire of coping strategies and may experience maturation, courage and vigour resulting from their hospitalisation experience (Langford, 1961; Boyd and Hunsberger, 1998). However, other authors assert that hospitalised CYPs have limited coping skills (Rokach and Parvini, 2011) and the frequency and effectiveness of their coping strategies are lower than for never hospitalised children (Board, 2005). Of note however, is that the sample in Board's (2005) study involved critically ill children, which may impact on the findings.

The literature suggests that hospitalised CYPs employ behavioural coping strategies such as behavioural distraction (e.g. listening to music), behavioural avoidance/resistance (e.g. going to sleep) and talking to others, particularly peers i.e. social support (Boyd and Hunsberger, 1998; Board, 2005). Additionally, CYPCCs are reported to utilise the following behavioural coping strategies: submission/resistance, emotional expression, verbal expression and information seeking (Boyd and Hunsberger, 1998).

Physical activity during hospitalisation, which can be regarded as a form of behavioural distraction, is associated with improved quality of life including both psychological and physical dimensions (Speyer et al., 2010). Furthermore, Savedra and Tesler (1981) suggest that CYPs employ different behavioural coping strategies at various points during their hospitalisation. The study indicates that CYPs utilise 'attempts to control' behaviours,

particularly after surgery, which involve suggestion or expression of an action which has not been suggested or directed by another. Many children used 'pre-coping behaviours', particularly prior to surgery, which refers to orienting behaviour by which CYPs familiarise themselves with the environment. However, a limitation of Savedra and Tesler's study is its over-reliance on parents' perspectives, rather than the CYPs themselves.

CYPCCs also utilise cognitive coping strategies in hospital, which include cognitive distraction (thinking about other things), avoidance (not thinking about hospital-related things), cognitive restructuring/maintaining a positive attitude, having confidence in hospital staff, fortitude and familiarity with hospital staff, routines and procedures (Boyd, and Hunsberger, 1998; Forsner et al., 2005).

Interestingly, the literature indicates that the narrative process is integral to hospitalised CYPs' coping. Engaging in narrative through talking/drawing/playing helps CYPCCs to assemble their experiences into an understandable form which allows them to share and communicate their experiences (Di Gallo, 2003). Furthermore, the narrative process allows CYPCCs to modify their (perhaps negative) experiences and identify positive aspects of hospitalisation in order to cope (Guzmán Sandoval et al., 2011). Interventions can assist CYPCCs to talk about and process their experiences and unique journeys (Scarfe et al. 2012).

There is a strong indication from literature that hospitalised CYPs do not cope alone, but that others such as hospital personnel, friends, family, and in particular parents, enhance

their coping (Pölkki et al., 1999; Forsner et al., 2005; Aldiss et al., 2009; Rokach and Parvini, 2011). However, Roberts (2010) identifies that not all CYPCCs have parental presence available as a source of coping, as many CYPs are unaccompanied in hospital for a variety of reasons, which can be detrimental for CYPs.

2.5.5. Summary

In summary, Section 2.5 outlined the key aspects of CYPCCs' experiences in hospital, including the importance of both the physical and social hospital environment. Literature suggests that although hospitalised CYPCCs want to be involved in consultation and decision-making regarding their own care, full participation rarely happens. CYPCCs experience a wide range of emotions when in hospital and there is a bilateral association between CYPCCs' emotional and physical wellbeing in hospital. Hospitalised CYPs employ a range of coping strategies, both behavioural and cognitive. Conclusions are somewhat supported by evidence from CYPCCs, as a large proportion of research concerning CYPs' experience of hospital, involve CYPs as primary informants, for example via qualitative interviews (e.g. Boyd and Hunsberger, 1998; Jensen et al., 2012; Lambert et al., 2014a).

2.6. Education of CYPCCs

2.6.1. Connectivity to school

For hospitalised CYPCCs, connectivity to the 'outside world' is of great importance, as noted in Section 2.5.3. Hospitalised CYPs need to feel socially connected, not only to the internal hospital community, but also externally to the outside world (Lambert et al., 2014a). It is

important for hospitalised CYPs to maintain links with school particularly as school attendance is often problematic for CYPCCs throughout their illness (Abrams et al., 2007) which decreases opportunities for academic success (D'Auria et al., 2000). Moreover, hospitalisation induces feelings of sadness and anxiety over missing school while also decreasing social opportunities and friendships, for which hospitalised CYPs also long (Rokach and Parvini, 2011). Yan et al. (1999) examined the self-concept among hospitalised Chinese CYPCCs and found that CYPCCs' self-concept (and most of its sub-concepts including social behaviour, academic competence and physical appearance) is significantly associated with academic achievement. The authors conclude that maintaining a hospital-school connection is important for hospitalised CYPs in order to continue their academic achievement and thus enhance their self-concept.

Technology can be used to widen the spectrum of CYPs' academic and social connectivity whilst in hospital (Lambert et al., 2014a). Wireless technology in particular can be instrumental in assisting CYPs to establish immediate connection with school and friends, which promotes positive health and wellbeing (Fels et al., 2003). However, research regarding the use of technology in assisting CYPCCs to connect to the outside world, could be considered outdated, given the rapid development of technology and the rise of social media, particularly among CYPs. Further (contemporary) research is needed concerning if and how hospitalised CYPCCs use technology to maintain connection with school.

2.6.2. Education for CYPCCs in hospital

Given the need for hospitalised CYPs to feel connected to the outside world, in particular school (and home), this section now explores learning for CYPCCs in the hospital setting, despite limited literature on the topic. This section also explores CYPCCs' reintegration to and inclusion in school.

2.6.2.1. Teaching and learning in hospital

Although teaching from HS teachers' perspectives, is not the research focus, it is necessary to consider the nature of HS teaching, to which hospitalised CYPCCs are subject. Literature indicates the vital role of HS teachers, not only in stimulating learning and keeping CYPs occupied whilst in hospital, but also maintaining a sense of normalcy for them, continuing a hospital-school connection (Wiles, 1987). HS teachers not only provide academic support in their role, through helping CYPCCs to catch up with missed school work (Lian and Chan, 2003), but also provide social and emotional support for hospitalised students (Watanabe, 2013). Burns' (2013) phenomenological study into the lived experiences of HS teachers indicates that teaching in HSs involves flexible prioritisation, primarily with scheduling, learning goals and objectives and curricular reorganisation. This is supported by DfE (2013a) which states that CYPs with medical conditions should access appropriate and flexible education suited to their needs, which is responsive to the CYP's changing health status. Additionally, teaching success is not defined by the teacher's accomplishments or academic assessments, but by the individual success stories of their students (Burns, 2013). Furthermore, this research points to the values-based role of HS teaching, in which the

focus is on the present in CYPs' lives, rather than attempts to predict CYPs' future (Burns, 2013).

Evidence suggests that technology can facilitate teaching and learning in HSs. Chin and Tsuei (2014) found that digital game-based learning is effective for increasing CYPCCs' motivation for learning and resuming their interaction with the social world. Furthermore, educational technologies provide access to flexible learning opportunities for hospitalised CYPs (Nisselle et al., 2012). In reality, digital technologies offer all CYPs, in or out of hospital, opportunities to "connect, establish meaningful relationships, access knowledge, create understandings and develop an identity and sense of belonging in the world" (Hopkins et al., 2014, p. 314). Hospitals must therefore embrace digital technologies into the hospital learning space to promote hospitalised CYPCCs' continuity of education (Hopkins et al., 2014). Furthermore, statutory guidance supports the use of electronic media, for example 'virtual classrooms' in providing broader curriculums for hospitalised CYPs (DfE, 2013a).

One key paper regarding CYPs' experience of learning in hospital is Crossland (2002). This exploratory case study investigates the influence of self-efficacy beliefs on the learning experiences of CYPs with cancer while in hospital. Not only does this study provide insights into CYPCCs' hospital learning experiences, but findings from the research strongly implicate education in hospital as an effective avenue through which CYPCCs can experience control, autonomy, and also achieve necessary developmental outcomes for successful psychosocial

adjustment. Table 8 summarises the key findings of this paper, in relation to hospitalised CYPCCs' self-efficacy beliefs and the impact of this on their learning.

Table 8: Summary of the factors found to impact on academic motivation and self-efficacy for CYPCCs in HS (taken from Crossland (2002) study)

Factor	Description
Expected length of time until return to school	Despite ability perceptions, hospital education was appreciated most when the general and primary objective of going back to school was nearby and therefore the purpose of the teaching was clear. When there was no imminent expectancy of returning to school, hospital education was seen as only moderately important and appeared to have only a marginal influence on CYPCCs' academic motivation.
Social interactions	For some CYPCCs, the motivational aspect of hospital education was the social interactions they had with HS teachers. The rapport between HS teachers and students was identified as a motivating factor in the children's academic pursuits, particularly given the hospitalised CYPCCs' increased sense of peer isolation.
Academic frustration	Academic frustration was most apparent with CYPCCs who had experienced academic success. For some CYPs being a good student was integral to how they saw themselves. Therefore, during difficult periods where the CYP was unable to maintain a high level of academic performance, the inability to achieve seemed to threaten their self-image and resulted in frustration for them.
Social comparison	CYPCCs receive education in an isolated and unique context and appear to require both positive and negative social comparative information. This information is necessary to evaluate their educational development in relation to their peer group, and from this self-assessment, form efficacy beliefs. In the absence of this social comparison data, CYPCCs relied heavily on teacher and parent feedback to facilitate their own self-assessment. CYPCCs appeared to consider teacher feedback as being important motivational academic efficacy cues. CYPCCs therefore responded positively to HS teachers' reinforcement and were disappointed by the absence of assessment marks/grades and formal reports.
Curriculum content and appeal	CYPCCs felt most academically efficacious when they understood the hospital education content and when the topic was appealing.
Inability to control the impact of their medical condition	The greatest source of academic anxiety was not CYPCCs' beliefs about their inability to control their performance outcomes, but in their powerlessness to control the impact of the illness on their physical and academic abilities and the challenges inherent in the educational context. Therefore, these students felt most academically efficacious and generally satisfied with their hospital learning experiences when they were feeling healthy.

In a context of limited literature regarding CYPCCs' learning experiences in hospital, Table 8 outlines some factors which impact on academic motivation and self-efficacy for CYPCCs in HS. Notably, in Crossland's (2002) study, CYPCCs believed that hospital was not an ideal educational context.

2.6.3. Connectedness – returning to school

Having explored literature on CYPCCs' learning in the hospital context, I now investigate literature relating to CYPCCs' re-entry to school, following periods of absence due to hospitalisation. First I review what is necessary for successful reintegration to school and secondly I explore how CYPCCs are included into school life, following re-integration.

2.6.3.1. Reintegration to school

To ensure successful reintegration to school for CYPCCs collaborative inter-agency working is required particularly between health and education professionals (Stuart and Goodsitt, 1996; Poursanidou et al., 2008; Chesire et al., 2011). However, Poursanidou et al. (2008) indicate the complexities involved which can challenge effective partnership between health and education professionals in supporting the reintegration of CYPCCs in England, such as attitudinal, institutional and wider political and economic factors. The researchers found, for example, that teachers' attitudes towards partnership with healthcare professionals were defensive, uninterested and reluctant. What's more, there was a lack of clarity regarding roles and responsibilities regarding CYPCCs from both education and health professionals' perspectives. Additionally, liaison with health professionals depends on the type of school

and its organisational culture (Dixon, 2014). Health-education liaison is more effective in primary and special schools compared to secondary and mainstream schools, where there are more difficulties (Poursanidou et al., 2008). Poursanidou et al. (2008) propose that for the provision of effective educational support for CYPCCs, hospital-school liaison needs to be proactive, preventative and systemic in nature.

To serve the needs of CYPCCs who require reintegration to education, schools need to demonstrate an avid commitment to accommodating their needs. For instance, teachers not only require additional training for working with CYPCCs, but schools also require a systemic transformation to allow for successful implementation (Cheshire et al., 2011). Moreover, schools must recognise the significance of school re-entry for CYPCCs, for example possibly as a time for medical disclosure or the reveal of a change in physical appearance (Dixon, 2014). Schools need not only to demonstrate sensitivity, but also provide the necessary support for CYPCCs to regain self-confidence, which is a defining factor in a CYP's re-entry to school (Dixon, 2014).

The importance of providing consistent educational provision during and after the period of education outside of school is highlighted by legislative guidance (DfE, 2013a). Furthermore, an individualised approach is necessary for reintegration (Georgiadi and Kourkoutas, 2010) for example establishing individually tailored reintegration plans, noting required reasonable adjustments (DfE, 2013a). This individualised reintegration process should view the CYP holistically, considering multiple aspects of the CYP's wider context (Worchel-

Prevatt et al., 1998). DfE (2014) states that reintegration should be supported by school documentation: school policy should include procedures for the process to be followed upon a CYP's reintegration to school and individual healthcare plans should identify the support needed by the CYP for effective reintegration.

2.6.3.2. Inclusion

Following re-integration to school, research indicates that CYPCCs may experience difficulties in being successfully included into school life despite legislation promoting CYPCCs' inclusion to the school community (DfE, 2013a). Watanabe (2014) suggests that CYPCCs have three areas of need upon their return to school, in relation to academic work, health and social-emotional wellbeing. Furthermore, hospitalisation and ill-health may have induced feelings of loneliness, anxiety, low levels of self-confidence and difficulties with peer relationships for CYPCCs (Watanabe, 2014). Dixon (2014) indicates that schools struggle to adequately deal with CYPs' experience of CCs as a continuing process over time and can struggle to manage incidents of bullying.

However, despite CYPCCs' wide-ranging needs in school, research suggests that schools have difficulties accommodating for this. From the 'Keeping Connected' longitudinal study¹⁰, White (2014) argues that enrolment of CYPCCs in full-time study and providing access to this education does not warrant inclusion; but rather inclusion is far more than this. Inclusion

¹⁰ The 'Keeping Connected' project was a 3 year longitudinal study in Australia which collected numerous data from 2007-2009. The project sought to improve practice for health and education professionals and parents of CYPs with enduring health conditions through investigating how disconnection occurs particularly across the areas of health and education.

encompasses the presence, involvement and success of all learners and emphasises populations of CYPs who may be at risk of marginalisation or underachievement (Ainscow and Miles, 2009). White (2014) argues that CYPCCs are an invisible and overlooked population in education, which is partly due to CYPCCs' desire to fit in and be perceived as 'normal', their small numbers in individual schools, and school practices' focus on performance rather than values-based concepts such as social justice (White, 2014).

Furthermore, barriers to CYPCCs' full inclusion into all aspects of school life include teachers' insufficient knowledge and skills in supporting CYPCCs in school, lack of communication, lack of information about the CYP's health condition, unsupportive school leadership and schools' fear of doing the 'wrong thing' (Dixon, 2014; Watanabe, 2014). Moreover, St Leger (2014) notes that practice regarding schools' accommodation for CYPCCs evolves over time and develops with each individual who experiences a health condition unfamiliar to the practitioners in the school.

In sum, there are numerous barriers to inclusion of CYPCCs in education, particularly as a result of school staff's lack of knowledge, understanding and experience of accommodating for CYPCCs. Yates (2014) proposes that inclusive education needs to consider more broadly the specific forms in which difference, marginalisation, power and exclusion affect groups of students.

2.7. Summary

This literature review has set the context for the current research. Firstly, existing literature concerning CYPs' experiences of living with CCs was explored. The review indicates that a pertinent issue for CYPCCs is a possible increased risk of emotional and social difficulties, although findings are inconsistent. This review of literature has indicated the critical role of systemic factors in CYPCCs' daily experiences in addition to the resilience of CYPCCs as a population, who are suggested to employ numerous coping strategies to address daily challenges.

This chapter has also highlighted an interesting body of literature in relation to the experiences of hospitalisation for CYPs. Findings mainly relate to the importance of the physical and social hospital environment to hospitalised CYPs' experience, as well as the need for hospitalised CYPCCs to be involved in consultation and decision-making regarding their own care, although full participation rarely ensues. This chapter indicated that CYPCCs can experience a wide range of emotions when in hospital and there is an association between CYPCCs' emotional and physical wellbeing in hospital. Hospitalised CYPs also employ a range of coping strategies, both behavioural and cognitive.

This literature review also highlighted several key issues in the area of education for CYPCCs, for example the necessity of maintaining a school-hospital connection, which is important for CYPCCs' self-concept and academic success. Learning opportunities are a legal requirement for hospitalised CYPCCs and despite limited research in this area, the role of HS

teachers appears multi-dimensional and the teaching and learning in HS is responsive to CYPCCs' needs. In this chapter I indicate the difficulties involved in i) successfully reintegrating CYPCCs into school following periods of absence due to hospitalisation and ii) successfully including CYPCCs into everyday school life. With regard to hospitalised CYPs' learning in hospital, this review has identified theoretical and empirical gaps, which the present study aims to address.

This chapter emphasises the importance of hearing CYPs' voices in research which is integral to an in-depth understanding of their health and hospitalisation experiences. Furthermore, it is also a matter of rights, in recognising and valuing CYPs' own agency in their experiences.

2.8. Justification for research

As this review demonstrates, there is currently existing research regarding CYPs' experiences of hospitalisation. However, what this chapter has also highlighted is the importance of the current study to address large gaps in existing research, particularly in terms of CYPs' experiences of *learning* in the hospital setting and the gathering of *in-depth* qualitative research regarding CYPCCs' hospitalisation experiences. Furthermore, the unique contribution of the current research is the educational perspective taken, as opposed to research from medical professionals and researchers, which currently dominates this field. The current research also takes a unique perspective in terms of listening to the voices of CYPs, the rationale for which is discussed in greater detail in Chapter 3.

3.0. METHODOLOGY

3.1. Overview

This chapter comprehensively details the methodology for the current study. Firstly, the research aims and RQs are outlined followed by an explanation of the philosophical approach (social constructionism) which underpins my selection of narrative inquiry for this study. Key features of narrative research and my rationale for selecting this approach are then explained in addition to details about the method: narrative interviews. Information is provided concerning recruitment of participants, the participants themselves and the ethical considerations adhered to in this study. Next, my efforts to maintain high quality research are evaluated. Finally, my approach to data analysis is detailed, including how I arrived at my data analysis decisions.

3.2. Research aims and research questions

Having identified gaps in existing literature in Chapter 2, the primary aim of this study is to explore the personal narratives of CYPCCs about their experiences of hospitalisation and HS.

The research focuses on CYPCCs' recollection of key events during the hospitalisation period, including their attendance at HS, and their evaluations of these experiences.

The study specifically aims to address the following RQs:

- 1. What are the meanings for CYPCCs of their experiences of hospitalisation?*
- 2. What are the meanings for CYPCCs of their experiences of HS?*

3.3. Philosophical approach

Research cannot be independent of the philosophical viewpoint held by the researcher, which directly influences and guides their research (Cohen et al., 2007). As a researcher with a social constructionist worldview, this is the approach I have adopted for this research. Ontology in research refers to beliefs held about the nature of social reality (Bryman, 2012) of which knowledge can be acquired. Social constructionism lies within the ontological position of anti-foundationalism (nominalism) which, in opposition to realism, asserts that phenomena and their meanings are subjectively socially constructed through language.

Epistemology refers to the nature of knowledge and how it can be acquired and communicated (Cohen et al., 2007). To gain knowledge about a socially constructed reality, it is necessary to adopt a social constructionist epistemology based in interpretivism. In contrast to some areas of traditional psychology, for example psychoanalysis and personality trait theories, social constructionism rejects the notion of 'essences' to people that make them who they are and which can be discovered, namely the notion of 'essentialism' (Burr, 2003). Rather, social constructionism posits that knowledge is socially constructed through interactions between people i.e. knowledge is a social process (Burr, 2003), which cannot be objectively 'discovered'. In terms of research therefore, it follows that the researcher and participant are both active contributors in the social co-construction of meaning. Social constructionism suggests that it is through the tool of language, as a form of social action, which versions of reality are co-constructed (Gergen, 1985).

3.4. Research methodology: narrative inquiry

3.4.1. What is narrative research? Definitions and key features

A pioneer of narrative psychology, Sarbin (1986), states that humans are born into a storied world and we live our lives through creating and exchanging narratives. He argues that upon presentation of several pictures or phrases, humans will intuitively connect and sequence them to form a story (Sarbin, 1986). This implies that as humans, we naturally and intrinsically create narratives. Narratives are not simply descriptions or ways of seeing the world, but it is through narratives that we actively *construct* our world and reality (Murray, 2008). Experience is therefore inextricably linked to narrative, with experience being the “stories people live” (Clandinin and Connelly, 2000, p. xxvi). Sarbin (1986, p. 8) refers to this as the ‘narratory principle’, that humans “think, perceive, imagine and make moral choices according to narrative structures.” Narrative approaches to research are increasingly popular because “stories reveal truths about human experience” (Reissman, 2008, p. 10). However, the notion that human experience assumes a narrative structure is disputed, as it is argued that narrative properties cannot be ascribed to real life (Crossley, 2002). Furthermore, Robson (2011) indicates that memory is selective which influences the construction of narratives and the potential omission of key events. However, for my research this is less of a limitation, as for me, the *meaning* individuals make of experiences, rather than a factual report of events (Bryman, 2012), is of greater importance. As Gergen (2004, p. 270) posits, social constructionists “did [do] not require that narratives be true or false in any absolute sense, but rather... renditions of events, cohering to certain cultural standards, which made sense of life to someone in a particular context.” It is also argued that the character of the broader social narrative within which narratives are created

influences the narrative produced (Murray, 2008). As Gergen (2004) explored the gendered nature of narratives and the impact of an individual's position in hierarchical social arrangements, I too argue that CYPs' position in society may be reflected in their narratives.

Narrative research approaches are vast, with conceptual differences related to the ontological and epistemological stances of the researcher and individual interpretation. Generally, narratives simply refer to the act of story-telling and key features of narratives are akin to stories, for example containing a depiction of events, experiences and emotions, humans as characters or actors, a plot leading to an emotional response (Bruner, 1990; Murray 2008; Reissman, 2008). Fundamental to the plot structure are characters' dilemmas/conflicts and attempted solutions to these difficulties (Sarbin, 1986).

Central to narrative, as with stories, is the concept of *time* (Elliot, 2005). Firstly, chronology is vital in narrative due to its inclusion of a beginning, middle and end (Cortazzi, 1993). Bruner (1990) defines narratives' composition of a unique *sequence of events*, a distinctive feature of the narrative approach. Reissman (2008) builds on this, proposing that individuals purposely construct this sequence of events ('plot') by selecting, organising, connecting and evaluating events. Not only is the sequencing of happenings (i.e. chronology) important, but also the idea of temporality, referring to the progression of time. Time is assumed to be 'unilinear' (Polkinghorne, 1995) and narratives can include ideas from the past, present and future (Clandinin and Connelly, 2000).

It is argued that humans use narratives to bring order and structure to an otherwise disorganised reality, which Sarbin (1986, p. 9) refers to as the 'organising principle for

human action'. In bringing order to disorder, a narrator attempts to make sense of and give *meaning* to experience and events (Murray, 2008; Crossley, 2010), which provides reassurance in affirming that life is ordered rather than a disconnected random array of events (Murray, 2008). Ricoeur (1984) refers to these attempts to restore order as 'emplotment', that is to say, organising a sequence of events into a plot. In organising events, the individual also attributes agency to the characters in the narrative and assumes connectedness and causality between events (Murray, 2008).

One crucial characteristic of narrative is its *contextual* nature. Individuals construct their narratives with reference to a chronology of events which is 'set within their personal, social, and historical context' (Creswell, 2007, p. 57). The storyline of the narrative may include information about the time, setting, place and scene of participants' experiences (Connelly and Clandinin, 1990; Reissman, 2008). Moreover, narratives are produced in and shaped by a specific context to create meaning for a particular audience (Elliot, 2005). Narratives are therefore context-dependent and incorporate known cultural discourses and values (Reissman, 2008).

3.4.2. Types of narrative research

Narrative research takes a number of forms (Creswell, 2007), particularly across disciplines (Robson, 2011) and there is no single way to conduct narrative research. Literature suggests five popular approaches to narrative research (Creswell, 2007; Murray, 2008; Robson, 2011), as outlined in Table 9.

Table 9: Popular approaches to narrative research as depicted by methodological literature

Narrative Approach	Description/ Purpose
Biographical	The researcher gathers information about the experiences of someone else
Autoethnographic/ autobiographic	Written by the participants themselves and contain the author's experiences as well as the wider cultural meanings of the story
Life history	These narratives depict entire life histories
Personal Experience	Used to explore experiences of individuals - either single or multiple episodes, private situations or common folklore - of an individual
Oral history	These are reflections on events, their causes and consequences

I opted to use a *personal experience* narrative approach for the present research. This is considered most appropriate for addressing my RQs, which focus specifically on the exploration of CYPCCs' reflections of their experiences of hospital, including HS (multiple episodes of one specific experience).

3.5. Rationale for narrative methodology

Creswell (2007) argues that narrative inquiry can be 'challenging' for researchers due to the necessity to gain a clear understanding of the context of participants' lives and for researchers' need to be self-reflective of their own perspectives and experiences which shape their interpretations and re-storying of participants' stories. Despite these challenges, I use narrative inquiry as my RQs lend themselves to this approach and a narrative approach will enable me to best gain an understanding of how CYPCCs make sense of their experiences of hospitalisation and HS.

Additionally, a narrative inquiry approach is well-suited to my research, exploring how hospitalised CYPCCs construct their experiences of hospitalisation and HS, for the following reasons. Narrative approaches are particularly appropriate for exploring the experiences of

people who experience illness, for example studies by Gergen and Gergen (1983) and Squire (2007), the latter involving narrative interviews with people affected by HIV. Narrative has been a particularly effective and influential approach to exploring the field of health and illness (Crossley, 2002; Bryman, 2012), particularly as illness is often regarded as disruptive and traumatic which can consequently significantly alter personal narratives ('narrative wreckages') (Crossley, 2002). Approaches with a social constructionist foundation are particularly suited to this population, given that illness and disability are often considered to be largely social constructs (Burr, 2003). Furthermore, narrative is effective for understanding experiences of disruption to everyday routines (Murray, 2008), of which hospitalisation can be regarded. Additionally, it is through personal narratives that we construct our own identities, particularly at times of instability (Murray, 2008). Narrative is central to our self-definition and how we conceive ourselves (McAdams, 1985).

In addition, currently little research adopts a narrative approach directly with CYPs. However, studies such as those of Blumenreich (2004) and more recently Prior and Niesz (2013) demonstrate that narrative can be effectively and appropriately used with this population, particularly when methodological adjustments are made (Prior and Niesz, 2013), as I have done in this study (see Section 3.6.5). My application of narrative methodology also contributes, therefore, to the sparse existing literature which employs narrative approaches with CYPs.

Lastly, narrative research is also in harmony with my personal values as a researcher, in holding empowerment and social justice in high esteem. Narrative research can be an approach with emancipatory potential, empowering participants and giving voices to the

unheard (Gergen, 2000; Blumenreich, 2004; Squire, 2008). Furthermore, participants may experience therapeutic benefits through narrating their experiences in a narrative interview (Murray, 2008). Specifically, Di Gallo (2003) indicates the importance of the narrative process for the coping of hospitalised CYPs, who are the focus of this study, in helping them to draw together their experiences into an understandable form which allows them to share these experiences with others.

3.6. Method: narrative interviews

3.6.1. Rationale

Interviews were judged as the optimal way of gathering narratives, when compared to other options such as seeking already-existing stories (e.g. written accounts - journals or letters) (Czarniawska, 2004), in order to best meet the research aims. Murray (2003) indicates that interviews are the primary source for generating narratives.

3.6.2. The narrative interview

Narrative interviews permit participants to provide accounts of specific experiences (Murray, 2008), with a key aim to generate rich, in depth, detailed narratives, rather than brief and rigid responses to questions (Reissman, 2008). Horsdal (2012, p. 75) indicates the uniqueness of narrative interviewing, as follows:

“The former [interviewee] is receiving a gift during this performance as the narrator consents to share her experiences and to allow the listener to accompany her on the journey she is travelling. Gifts should be treated with care and respect.”

From this, the empowerment aspect of the narrative interview becomes apparent, with the participant holding the power as gatekeeper and owner of their narrative account. Empowerment does not mean participants are the sole power holders, but instead refers to the equalising of power between researcher and participant, which from my social constructionist epistemological stance is vital for co-constructing stories (a 'narrative occasion'; Reissman, 2008). With the interviewer-interviewee power balance restructured/shifted in this way, Mishler (1986a) argues that participants are likely to produce narrative accounts. I therefore consider empowerment as central to the development of the narrative interview design for this study.

3.6.3. Narrative interview guide

Several key recommendations were identified as instrumental to the interview design and conducting of the interview and were thus considered in the development of the narrative interview design (see Table 10).

Table 10: Recommendations from literature which influenced the development of the interview guide for this research

Recommendation	Purpose
1. The use of jargon should be limited, with preference for everyday language (Elliott, 2005).	Balance of power
2. Open questions should be asked (Elliott, 2005; Reissman, 2008) instead of closed or leading questions.	It is important for researchers to reduce their control and follow participants down their own trails (Reissman, 2008).
3. It is important to build a rapport with participants prior to interviews and clarify expectations of the interview (Elliott, 2005).	Stories develop within certain social contexts and vary according to contextual factors, including the relationship with audience members (Murray, 2008) and therefore the interviewer-interviewee relationship is significant. Additionally, it can take time to build participants'

Recommendation	Purpose
	confidence that detailed stories about their experience are useful/meaningful in this context (Holloway and Jefferson, 2000). Furthermore, Murray (2008) argues that some participants find it difficult to believe that the researcher is genuinely interested in hearing their story.
4. The researcher should not offer an exchange of views during the interview (Czarniawska, 2004), nor interrupt the interviewee during the narrative telling process (Horsdal, 2012).	The researcher should not convey judgement, but instead should be respectful and attentive co-constructors (Czarniawska, 2004) who are responsive in their choice and use of questions as well as non-verbal communication such as nods and silences (Kvale and Brinkman, 2009). In addition, interruption during the interview may alter the narrative structure and plot (Horsdal, 2012).
5. Interviews should not suppress narratives (Mishler, 1986a) but allow participants to tell their stories as fully as possible.	The role of the researcher is to give participants the framework and space to generate rich detailed narratives (Murray, 2008).

As discussed in Section 3.6.1, I decided to elicit participants' stories through face to face interviews for this research. Narrative interviews vary in format, ranging from an open single question approach (Wengraf, 2001), in which the interviewee holds most of the talk, such as in life story narratives (Horsdal, 2012) to a more dynamic mutual 'conversation' approach (Reissman, 2008) to a more structured approach with specific key questions (McAdams, 1993).

I opted to use episodic interviews which focus on a particular episode in a participant's life, rather than their whole life history (Murray, 2008; Kvale and Brinkman, 2009). An episodic approach to the narrative interview is beneficial as the interviewer can co-construct rich and detailed narratives (Flick, 2000) about specific situations and episodes in relation to the research focus and aims (Flick, 2014). An episodic approach was considered most

appropriate for this study as the research focus is about CYPs' perceptions of their experiences at hospital and HS, which I consider as *multiple episodes of the same experience*, rather than a single episode. This understanding may contrast with alternative interpretations of what constitutes an 'episode' in narrative research. Flick (2000) for example suggests that an episode in narrative research could involve an interviewee recounting how they learned how to ride a bike, which may be a single event. However of significance, Flick (2000) also identifies what he terms 'repisodes' which are regular and repeated occurrences of situations, as is the case with my research. My interpretation of 'episode' in episodic narrative research is perhaps broader than more rigid 'traditional' definitions of an episode, with clear temporal boundaries. This is not the case with the present research, as participants' experiences of hospitalisation and HS vary considerably in terms of time span. In line with the ideas offered by Flick (2000; 2014), I argue that an episodic approach to the current research allows for a more concrete approach, specifically relevant to the RQs, than does a life history approach.

I also chose to adopt a fairly structured format to the interview, with key questions, as this was considered beneficial for the participants, as CYPs, to scaffold and break up the expectation for a long continuous narrative, which some CYPs may be unaccustomed to and find challenging. I anticipated that asking specific questions would generate more detailed and in-depth narratives.

I adapted McAdams' (1993) narrative interview because it focuses on key events, which despite its intended use for life history research (Crossley, 2010), offers an approachable and interactive collaboration between participant and researcher. The protocol also proposes an appealing seven question narrative interview structure, including questions which require the participant to reflect on key events throughout their experiences (Box 1).

Box 1: McAdams (1993) interview protocol

1. Life chapters
2. Key events
 - Peak experience (a high point - most pleasant moment in life).
 - Nadir experience (a low point - worst moment in life).
 - Turning point (an episode of significant change in which the interviewee changed their understanding of her/himself).
 - Earliest memory (one of earliest memories - setting, characters, thoughts and feelings)
 - An important childhood memory (any memory from childhood, positive or negative that stands out)
 - An important adolescent memory (any memory from teenage years, positive or negative that stands out)
 - An important adult memory (any memory from age 21 onwards, positive or negative that stands out)
 - Other important memory (one particular event from either recent or distant past, positive or negative, that stands out).
3. Significant people
4. Future scripts
5. Stresses and problems
6. Personal ideology
7. Life Theme

Alterations were made to McAdams' narrative interview guide in relation to the participants' developmental level and the RQs. The adapted interview schedule for this research is outlined in Table 11 below, which also details the rationales for these alterations. See Appendix 2 for the full interview guide and the interviewer script.

Table 11: Interview guide adapted from McAdams (1993) for the purpose of this research

Interview guide	Explanation and/or justification for adaptations
1. Life Chapters	<p>CYPs were asked to think of between 2- 8 life chapters to plot onto a visual storyboard. If the participant found this too challenging, it was anticipated that the task would be simplified to just 3 chapters, called 'beginning', 'middle' and 'end'.</p> <p>This was considered a useful part of McAdams' (1993) interview protocol as it required participants to divide up their experiences of hospital and HS into spans of time as they deemed appropriate. It also gave participants the opportunity to select and evaluate key occurrences in each chapter.</p>
2. Key events: <ul style="list-style-type: none"> ○ Peak experience (a high point since hospitalisation and attendance at HS) ○ Nadir experience (a low point since hospitalisation and attendance at HS). ○ Turning point (an episode involving significant change in interviewees' understanding of themselves). 	<p>All 'key events' questions have been adapted to fit the 'episodic' nature of the interview guide, rather than the life story approach McAdams intended. That is to say, all questions relating to key events specifically refer to participants' experiences of hospital and HS, rather than their entire lives.</p> <p>Questions intended for use with adults, which ask them to reflect on various developmental stages of their life, i.e. 'an important childhood memory', 'an important adolescent memory' and 'an important adult memory' have been omitted from the interview guide as they are less relevant for CYPs. Furthermore, 'earliest memory' has also been omitted as the three selected 'key events' were considered to be more important.</p> <p>The three selected 'key events' questions were selected because by their very nature, they require participants to evaluate their memories, for example judging their best/worst memory. This is important in addressing the RQs, which particularly focus on participants' sense-making and evaluations of their experiences.</p>
3. Significant people	<p>This question was a key part of the interview guide for this study. This is due to its inherent evaluative quality which relates to the RQs. This question asks participants to reflect on people who have significantly impacted on their time in hospital, either positively or negatively.</p>
4. Future scripts	<p>This question was originally excluded from the interview guide due to the possibility of distress if participants had not thought about the future or considered it would be bleak. However, it was decided that it was best to give participants the option of answering this question or not, based on how they felt about it at the time. This question was important as it could reveal the perceived impact of participants' experiences on their future. All participants chose to answer this question.</p>
5. Stresses and problems	<p>This question was excluded in the interview guide for ethical reasons. I did not want to intentionally ask the CYPs to think about (persistent and on-going) problematic experiences, in addition to asking them about their (single) worst memory. It was anticipated that stresses and problems may</p>

Interview guide	Explanation and/or justification for adaptations
	be discussed organically as CYPs' narratives emerged.
6. Personal ideology	This question was omitted from the study due to its complexity, which I thought may be challenging for some participants.
7. Life theme	Participants were asked to think of a 'life theme' as the McAdams interview protocol recommends. I asked participants to think of a title for their personal film/book. This was considered useful in giving participants the opportunity to reflect on their narratives as a whole.

In addition to evaluating the type of narrative interview to be used in this research, it was also necessary to consider the age and developmental level of the participants, regarding the interview process (see Section 3.6.5).

3.6.4. CYPs in research

Literature suggests that CYPs have a place in research and the importance of listening to the voice of CYPs is becoming increasingly prevalent (Davies and Lewis, 2015). Indeed, CYPs have the right to be heard on matters which affect them, which includes their involvement in research (Curtin and Murtagh, 2007; Daley, 2015). The UN Convention on the Rights of the Child Article 12 clearly states this right and it is further reflected in UK legislation such as the SEN Code of Practice (DfES, 2001) and more recently the Children and Families Act (2014). Besides, not only do CYPs have the right to be involved in research, but can also offer valuable insights and are thus 'worth' researching. Daly (2009) proposes that capturing CYPs' views ensures that research is of benefit to other CYPs, as well as policy makers and practitioners. The voice of CYPs is integral to this study and despite limited narrative research with CYPs, when this approach has been adopted with this population, evidence

suggests that narrative is effective for exploring CYPs' experiences. Appendix 3 details further information regarding CYPs' role in research, including narrative research.

3.6.5. Interview process

Prior to data collection, I engaged in field-testing, which involved conducting an interview with a hospitalised CYPCC. This is recommended to rehearse interviewer skills (Gillham, 2000) and refine the research instrument as necessary (Creswell, 2013). The interview guide was deemed appropriate for effectively eliciting the narratives of CYPCCs and thus no adaptations were made to the interview questions. This interviewee's narrative was therefore included in the overall data collected. However the field-testing led me to revise my own practice, allowing even longer and more frequent pauses, to provide more space for narrators' creation of narratives (Mishler, 1986a).

Interviews lasted between 30 and 60 minutes, although this is not necessarily representative of the exact time spent in dialogue due to the frequent interruptions during the interviews. Although all participants were offered the opportunity to have the interview over more than one session, this was not considered necessary by any of the participants and the entire interview guide was completed in one session for all participants. Several authors suggest that 90 minutes is the optimum length for narrative interviews (Elliott, 2005), however the nature of the interviewees' health needs and their age needed consideration. It was judged that interviews would last approximately 30 minutes based on

other studies with CYPs as interviewees (such as Forsner et al., 2005). Notably, CYPs appear to be ignored in literature regarding the length of narrative interviews.

Interviews can be described as ‘narrative occasions’ in which two active participants collaboratively construct narratives and meaning (Elliott, 2005; Reissman, 2008). To this end, this joint encounter involved my demonstration of attentive listening, using both non-verbal cues, such as responsive facial expressions, head nods, eye contact (Gillham, 2000) and verbal phrases such as “mm hmm” and “okay” (Mishler, 1986b) to indicate interest. Follow up questions such as ‘tell me what happened’ followed by ‘and then what happened’ were used, as these types of questions are well-suited to eliciting narrative accounts (Bryman, 2012). Follow up questions also focused on cognitions and feelings, to encourage participants not only to recount their experiences, but to evaluate them.

Furthermore, efforts were made to create an environment amenable to storytelling. For instance, it was necessary not to suppress participants’ narratives, and I did this by not interrupting (Elliott, 2005) and by promoting the greater balance of talking to be with the CYPCCs (Reissman, 2008). The creation of a storytelling milieu was particularly vital due to CYPs’ expectations in social situations involving a child and an adult and the possibility of power imbalances between adult researchers and participants who are CYPs (see Table 12).

Interviews were audio-recorded with participants’ consent, as is regarded best practice (Elliott, 2005). It was considered impractical to attempt to remember interviewees’

responses or pause to take notes (Elliott, 2005) and I preferred instead to give my full attention to participants during the interview. Field notes were taken however, particularly before and after the interviews, regarding my initial reflections, the interview context (see Section 3.9), additional conversation after the audio recording had finished and any other relevant information, which is recommended (Creswell, 2013). Literature suggests that when interviewing CYPs, several considerations should be made, which are outlined in Table 12.

Table 12: Recommendations in literature about interviews with CYPs and applications to the present study

Recommendations	Authors	Application to present study
1. The researcher should attempt to build a rapport/relationship with CYPs, preferably prior to interviewing them. This rapport is important as it encourages CYPs to be more forthcoming with their responses and to establish a sense of trust. It is important to put CYPs at ease.	Begley (2000); Costley (2000); Lewis and Lindsay (2000); Kellett and Ding (2004)	<ul style="list-style-type: none"> • I attempted to meet with all participants prior to the interviews taking place, in order to initiate familiarisation between myself and the interviewees and so that they understood my genuine interest in their experiences. • The first few questions of the interview guide were not particularly focused on the research aims, but were 'warm up' questions, for the purpose of building rapport with the CYPs. The questions focused on neutral topics, for example what their favourite subjects were at school and what they enjoyed doing in their spare time. The aim was to help the interview process be more comfortable for CYPs. • I used a storyboard framework, which was a familiar task to CYPs, which would help CYPs to feel at ease. Begley (2000) suggests that the strangeness of the interview situation can be lessened by adopting methods which are less threatening, more familiar and more fun to CYPs.
2. Researchers should be aware of the	Begley (2000); Costley (2000);	<ul style="list-style-type: none"> • CYPs' expectation of brief question-answer adult-child dynamics, in which CYPs are not

Recommendations	Authors	Application to present study
difficulties when interviewing CYPs in relation to issues of status, position and power differentials between adult researchers (interviewers) and participants who are CYPs.	Robinson and Kellett (2004)	<p>expected or required to produce extended responses, as with the typical structure of teacher-pupil talk in the classroom (Dockrell et al., 2000), does not lend itself to the creation of narratives. I therefore employed additional efforts to rebalance the power and relational dynamics to facilitate the co-construction of CYPs' narratives.</p> <ul style="list-style-type: none"> • At the beginning of each interview the purpose of the research was explained once more to pupils to attempt to allay possible feelings of apprehension and reiterate their right to withdraw during the interview if they wished. • I explicitly stated to CYPs prior to the interviews that there were no right or wrong answers to decrease the likelihood of CYPs simply providing responses they thought I wanted to hear. I made it clear to the CYPs that it was <i>their</i> story I was interested in hearing, which I considered to be an empowering aspect of the narrative interview. • To permit the CYPs more power in the research process CYPs were allowed to complete the tasks at their own pace and were not stopped/interrupted when speaking, even if they talked about matters not directly related to the RQs.
3. CYPs may experience difficulties with receptive and expressive language and may also have difficulties sustaining attention in interviews.	Begley (2000)	<ul style="list-style-type: none"> • Language used in the interview was simplified according to the language needs of the CYP. If it was evident that the interviewee did not understand a question, I attempted to rephrase it and/or provide verbal prompts for CYPs. • I attempted to avoid jargon and terminology unlikely to be familiar to CYPs.
4. Flexible and creative approach to eliciting CYPs' views by adapting interview methods	Kellett and Ding (2004); Lewis and Porter (2007)	<ul style="list-style-type: none"> • When meeting with participants prior to the interviews, a range of possible methods for eliciting their views were discussed, of which they could express preferences. • During the interview, colourful storyboards and shapes were used (see Appendix 4 for interview resources) to facilitate the

Recommendations	Authors	Application to present study
		<p>participants' narrative telling and engagement in the interviews. Storyboards were used due to CYPs' assumed familiarity with them from educational activities. Furthermore, the storyboard format easily lent itself to the creation of 'chapters' for CYPs, which was a necessary part of the interview. Participants were informed that they could write, draw and decorate their story boards, or they could ask me to help with this if they preferred. Three out of five participants chose the latter option, and asked me to write and decorate the story boards, under their specific instruction.</p>
<p>5. CYPs may respond to questions, even if they are unsure of the answer, due to school 'conditioning' in which children are encouraged to attempt to answer questions, even when they are unsure.</p>	<p>Kellett and Ding (2004)</p>	<ul style="list-style-type: none"> • In the interviews, I permitted the use of 'don't know' answers from participants and made it clear that this was an acceptable response. Some interviewees did indeed take up this option. I also further emphasised to participants that there were no right or wrong answers. • In the interviews, I explained my role as a TEP and as a researcher and explicitly stated that I was not a teacher, to avoid role confusion for CYPs.
<p>6. Researchers may underestimate the length of time CYPs take to respond to questions. Listening skills are crucial.</p>	<p>Kellett and Ding (2004)</p>	<ul style="list-style-type: none"> • During the interviews, I ensured that I provided sufficient time for CYPs to respond, resisting the temptation to break the silence. I sought to demonstrate to the CYPs that I was interested in their views and that I was prepared to employ patience and truly listen to what they were saying.

3.7. Evaluation of research

Traditionally, the terms 'validity' and 'reliability' originate in the natural sciences and are associated with positivist paradigms (Elliott, 2005). Validity refers to the ability for research to reflect an external reality or to measure the concepts of interest, and reliability refers to the ability for research findings to be replicated (Elliott, 2005). Some authors argue that such terms and their associated criteria are inappropriate for qualitative research and propose alternative ways for evaluation (Webster and Mertova, 2007; Reissman, 2008; Creswell, 2013), as I have chosen to do also. Despite possible difficulties with terminology and criteria, Elliott (2005) nevertheless argues that it is essential for social scientists to confront challenges regarding the stability, trustworthiness, and scope of their findings.

Without entering into a 'paradigm war' which Reissman (2008) regards as simplistic and unhelpful, I agree that it is unsatisfactory to apply traditional criteria of validity and reliability to narrative research. Polkinghorne (1988) argues that narrative researchers need to 're-orientate' evaluation measures, particularly as narrative researchers give justification of validation to a different kind of claim, about the meaning life events hold for people, rather than ones based on realist assumptions (Polkinghorne, 2007). This section details the actions taken to heighten the quality of the current research.

3.7.1. Trustworthiness

For interpretative studies, validation is judged in terms of the ‘trustworthiness’ of the research (Angen, 2000) and is an attempt to assess the ‘accuracy’ of research findings (Creswell, 2013). Polkinghorne (1988) refers to the validity of narrative research as ‘well-grounded and supportable’ conclusions. Validation is a process (Angen, 2000) and is a matter of argumentative practice, rather than simply about ‘mechanics’ (Polkinghorne, 2007).

Although some interpretative researchers have little use for validation (Wolcott, 1990), I deemed it a necessary part of the present study. Table 13 outlines the actions taken to enhance the trustworthiness of this research, having considered recommendations from literature. The table considers trustworthiness at two levels, as is necessary for narrative research (Reissman, 2008), namely i) the narrative told by the interviewee and ii) the analysis or the story told by the researcher. Reissman (2008) notes that validity must be considered within the researcher’s ‘situated perspective’, and thus the considerations in Table 13 are within the context of the underpinning ideas and traditions which frame this research.

Table 13: Measures taken to improve the trustworthiness of the study, based on recommendations from the review of literature

Criteria relating to evaluation of trustworthiness	Authors	Measures taken in the current research
<i>Are the data produced by qualitative interviews accurate?</i>	Elliott (2005)	<ul style="list-style-type: none"> • The narrative interview, as used in this study, produces data that are more accurate, truthful and trustworthy (Mishler, 1986b; Cox, 2003) than other types of interview. • The conduct and process of the narrative interview in this study encouraged participants to talk about what they themselves considered most important and to construct their storytelling in ways most suitable for them. Cox (2003) argues that this results in more accurate and valid evidence.
<i>Are claims made by the researcher justified for persuading the reader? Is the interpretative work coherent?</i>	Polkinghorne (1988); Yardley (2000); Polkinghorne (2007); Reissman (2008)	<ul style="list-style-type: none"> • Descriptive evidence from interviewees' accounts is cited to support claims and conclusions, including the use of direct quotations from participants (see Chapters 4 and 5). • Primary data is available to readers, namely exemplary transcripts (including one analysed transcript) from which claims are made available in Appendices. • Descriptions are provided for the context in which the research takes place so that readers are provided with the research context, to which claims relate (see Section 3.9 and Appendix 7). Reissman (2008) argues that interview segments which include contextual information about the production of the data make the arguments more persuasive. Furthermore, in order to enable readers to access the participants, cultural contexts and the context in which the process of co-construction of knowledge took place between myself as researcher and participants (Webster and Mertova, 2007) are provided. • Negative or disconfirming evidence is reported in addition to evidence supporting claims (Reissman, 2008; Creswell, 2013). This is for the purpose of providing a realistic assessment of the phenomena being studied and also is a way to provide ultimate transparency regarding how conclusions were reached, in light of negative or disconfirming evidence. • Alternative interpretations considered are reported in the write up, in addition to reasons for why the interpretation arrived at is more likely than other possible interpretations (Polkinghorne, 1988). Reissman (2008) argues that academic audiences need to know why the

Criteria relating to evaluation of trustworthiness	Authors	Measures taken in the current research
		researcher arrived at some conclusions and not others.
<i>Are the findings of the study generalizable?</i>	Elliott (2005); Creswell (2013)	<ul style="list-style-type: none"> I engaged in 'rich, thick description' (Creswell, 2013), which involved detailing the participants and the setting in the study (Sections 3.8 and 3.9). This provides a sufficient base to enable readers to transfer information to other settings to determine whether the findings can be transferred because of 'shared characteristics' (Lincoln and Guba, 1985; Creswell, 2013).
<i>Does the researcher demonstrate substantive validation? i.e. understanding of one's own topic</i>	Angen (2000)	<ul style="list-style-type: none"> A comprehensive and systematic literature review was conducted in relation to the research focus (Chapter 2) which demonstrates a thorough and well-grounded understanding of the topic. Self-reflection is demonstrated throughout the research, improving the integrity and criticality of the research. Reflexivity is also a key part of the research and is demonstrated throughout the research process, particularly with regard to data collection and data analysis processes.
<i>Does the researcher seek consensual validation?</i>	Eisner (1991); Webster and Mertova (2007); Creswell (2013)	<ul style="list-style-type: none"> During the research process, supervision was regularly sought in order to gain the (critical) opinions of a knowledgeable other. I engaged in 'peer reviewing/debriefing' (Creswell, 2013) during supervision as an external check of the research process by way of my supervisor acting as a 'critical friend' and 'devil's advocate'. Critical others contribute to the integrity of knowledge (Webster and Mertova, 2007).
<i>Does the researcher demonstrate transparency so that readers are able to judge the trustworthiness of the research, including the meanings/conclusions arrived at the end of the research?</i>	Reissman (2008); Creswell (2013)	<ul style="list-style-type: none"> In the write-up of this research, there are detailed descriptions of all stages of the research process. This includes explicit details about the selection and recruitment of participants (Section 3.8.1), data collection procedures (Section 3.6), transcription and data analysis process (Section 3.12). All of these include explicit rationales for the methodological decisions made, for example regarding research design and data analysis and why these choices were selected in favour of other similar alternatives. All decisions and interpretations have been well-documented throughout the write-up, leaving an audit or evidence trail for the arrival of interpretations and conclusions to be judged by

Criteria relating to evaluation of trustworthiness	Authors	Measures taken in the current research
		<p>readers.</p> <ul style="list-style-type: none"> • A diary/log was kept throughout the duration of the research project, as recommended by Reissman (2008). This demonstrates methodological awareness, critical self-awareness, and reflexivity and leaves an audit trail for decisions made. • Primary data are made available for readers' consultation in the Appendices.
<i>Does the researcher clarify researcher bias?</i>	Creswell (2013)	<ul style="list-style-type: none"> • The influence of the researcher and the importance of reflexivity are thoroughly discussed (Section 3.10). • My philosophical stance, social constructionism, which guides and influences all aspects of the research is outlined in Section 3.3. • Details about my personal background are provided for readers (Chapter 1). Therefore, ways in which my background experiences have produced understandings through interaction with the text are made explicit (Polkinghorne, 2007). Moreover, my personal background and its impact on my interpretations of findings are further explained in Chapter 4.
<i>Does the narrative research contribute to social change? Does the research foster social justice? Does the research lead to dialogue and change concerning participants, researchers and theory?</i>	Lincoln and Guba (1985); Yardley (2000); Reissman (2008); Creswell (2013)	<ul style="list-style-type: none"> • A clear rationale is provided for the present research (Section 2.8) which outlines the intended impact and significance of the research and reasons for embarking on this area or academic study. • The research contributes to existing literature in this field, which is highlighted in the Discussion (Chapter 5). The Literature Review (Chapter 2) clearly identifies gaps in existing research, which the present study addresses. • Implications for both practice and research are clearly identified and discussed (Sections 5.4 and 6.3 respectively). • The contribution and impact of the study is clearly discussed (Section 6.2).

3.7.2. Dependability

‘Reliability’ in traditional natural scientific research refers to the ability for research findings to be replicated and yield similar findings, which places importance on consistency and stability of measurements. In interpretative research however, rather than seeking reliability, it is ‘dependability’ of findings that is of greater importance (Polkinghorne, 1988; Creswell, 2013). Although narrative research may be more successful than quantitative approaches concerning validity judgements, reliability is more difficult to achieve for narrative research (Webster and Mertova, 2007). It is my view that narrative interviews are not intended to produce data that are stable over time, as by its very nature it may be subject to change and instability. As Reissman (2008) notes, narrative accounts have ‘shifting meanings’ over time. However, I consider this not to be a weakness of narrative; but a strength and in my pursuit to understand individuals’ experiences and the impact of these experiences, I also acknowledge and value that the research’s findings reflect the storytellers’ truth at a particular point in time, and in a specific context.

Methodological literature indicates that to establish dependability, the research process must be thoroughly audited (Creswell, 2013). Lincoln and Guba (1985) recommend that researchers maintain complete records regarding all phases of the research, including participant selection, field notes, transcripts and data analysis decisions. This was the case for the present study, as is detailed more fully in Section 3.7, in which every stage of the research process is carefully documented and subject to critical appraisal throughout.

Huberman (1995) posits that if narrative researchers employ rigorous methods of reading and interpreting so that other researchers are able to trace their conclusions, then reliability, in terms of access and honesty is possible. Furthermore, Webster and Mertova (2007) suggest that reliability in narrative research is assessed by the accuracy and accessibility of the data. To this end, primary data in the form of transcripts, analysed transcripts and direct quotations (which were used to support claims) were made available for readers.

Polkinghorne (1988) refers to dependability of qualitative research as the trustworthiness of field notes and transcripts. To this end, I audio-taped interviews (with consent), which enabled detailed interview transcripts to enhance the reliability of research (Creswell, 2013).

3.7.3. Additional criteria

I acknowledge that other criteria (than those discussed in Sections 3.7.1 and 3.7.2) can be considered to judge the quality of interpretative research. Several authors propose ethical criteria by which to assess the merit of research, for example protecting the confidentiality of participants (Howe and Eisenhardt, 1990; Reissman, 2008). The present research demonstrates rigorous ethical standards throughout the research process, including participant selection, data collection processes and data analysis. Ethical considerations and challenges are discussed in detail in Sections 3.11 and 6.5.2 respectively.

Another criterion used to judge research is aesthetic merit (Richardson and St. Pierre, 2005; Reissman, 2008). To this end, I have approached the research creatively, using interesting analytical practices to interpret the data and interesting ways to present my findings and capture the reader. Emotional criteria can also be used for assessing research quality (Reissman, 2008; Creswell, 2013). Clearly, it is not fully in my control whether or not readers are moved emotionally by this research. However I present my findings in a way that encourages the reader to think differently about the topic and encourages a move to action (e.g. new research practices or practice-related action). Moreover, I use direct quotations and introduce the participants to the reader, in order to bring the study to life. Richardson and St. Pierre (2005) propose reflexivity, in itself, as a criterion to judge research. In this study, I demonstrate self-awareness and self-exposure throughout the research (for example in Sections 1.2 and 4.2), which is an integral aspect of this study. I am explicit about my own influences and inherent subjectivity, which have guided research decisions. I hold myself accountable for the conveying of stories told by participants in this study.

3.8. Participants

This section focuses on the participants, who are central to this research. The researcher must initially identify interviewees who can best answer the RQs (Miles and Huberman, 1994). For this research, regarding hospitalised CYPCCs, it was clear to me who were best positioned to address the RQs - hospitalised CYPCCs themselves, who are experienced with hospitalisation and HS. Firstly, this section explores participant recruitment and selection and then introduces the individual CYPCCs themselves, which is important given the diversity of participants' experiences, despite all sharing exposure to hospitalisation and HS.

Holloway and Jefferson (2000) suggest descriptive 'pen portraits' in which the participants not only 'come alive' for the reader, but also provides information about each person so that comments made about the participant are meaningful for the reader. Information in the pen portraits are from participants themselves, based on rapport building questions at the beginning of the interviews. No information from others (e.g. parents, HS teachers) is included in the pen portraits, as I have retained the power with the participants. Although most participants have been discharged from the setting, care has been taken regarding the level of detail in the pen portraits, for ethical (confidentiality) reasons.

3.8.1. Recruitment and selection

To identify the context for which the research would take place, I approached EPs in the LA in which I was placed, as a TEP. An EP with experience working in the local HS was identified and jointly we contacted the key person of the HS. This was beneficial as the EP knew the key person to contact for the research and she was familiar to HS staff. A meeting was then arranged with myself and the Head of the HS to discuss the purpose and nature of the study and invite the school to be involved in the research. Questions the HS staff had at this time were addressed in this meeting.

The Head of the HS and an assigned clinical team member then acted as gatekeepers for the research to ensure ethical recruitment of participants. Information sheets for parents¹¹

¹¹ This information sheet explains in detail the research purposes and requests volunteers (BPS, 2010; BERA, 2011). Furthermore, the information sheet details procedures for maintaining confidentiality and participants' right to withdraw (BPS, 2009; BERA, 2011).

(Appendix 5) were given to HS staff for distribution to parents/carers of CYPCCs who met the selection criteria (see Table 14). Any parents/carers (who would have discussed the research with their children) who indicated interest in their children participating in the research were asked to contact the Head of the HS. Liaison between myself and HS staff then ensued to arrange suitable times for interviews. Additional face-to-face meetings were also offered for parents/carers who wished to discuss the research opportunity further.

Prior to arranging interviews, individual meetings were held with CYPs whose parents/carers had given written consent, with parents/carers present if preferred. These meetings were to explain the research to CYPs both verbally and in written form and requested volunteers to participate in the study. It was emphasised that the interview was not compulsory and that CYPs had the right to withdraw at any time during the interview (British Psychological Society (BPS), 2010; British Educational Research Association (BERA), 2011). An 'opt-in' convenience sampling approach can be criticised for providing a biased sample (Thomas, 2013). However, I considered an opt in approach best as CYPs' active participation in the research and enthusiasm may have meant that CYPs spoke more extensively about their experiences, generating full and rich narratives. Moreover, I considered this approach more ethically sound. However, it is contestable whether CYPs were really the ones 'opting in'. Although all participants appeared comfortable and willing to talk, CYPs may have felt obligated to participate in the study, having been informed that their parents/carers had already consented to their participation. My presence may also have inadvertently influenced CYPs' participation. This brings in to question whether the CYPs' involvement in

the research was truly voluntary (Fox, 2013). Coyne et al. (2009) emphasise the need for CYPs to choose whether or not to participate in research in the truest sense.

Potential participants were identified by HS staff and the clinical lead, using the selection criteria identified in Table 14. In total, five participants were recruited for the study, which was the initial goal. Literature differs greatly with respect to the number of participants suggested for a narrative inquiry. Creswell (2013) for example recommends up to three individuals for narrative research, whilst Williams (1984) included 30 respondents in his study. It was thought best to consider other similar studies, which also sought in-depth interview data from CYPs, which suggested that five participants was suitable¹². Although CYPs may produce rich narratives, the data may be less than for adult participants. It was therefore important to balance gathering sufficient data for the study and affording voices to hospitalised CYPCCs, whilst also ensuring not too much data which would detract from in-depth, detailed analysis.

Although five participants were suitable for the current study, it was vital that CYPs were not excluded from the research if they wished to participate. Thus, a letter was distributed (Appendix 6) to remaining identified potential participants (via HS staff) to provide opportunities for those who still wanted to be involved in the research.

¹² Examples of other studies considered includes: Boyd and Hunsberger (1998) (n=6), Coyne (2006) (n=11), Guzmán Sandoval et al. (2011) (n=5), Forsner et al. (2009) (n = 9), Forsner et al. (2005) (n = 5), Jensen et al. (2012) (n =8)

Table 14: Inclusion and exclusion criteria utilised for the selection of participants

	Criteria	Rationale
Inclusion	CYPs aged 8: 0 – 16: 11	Developmental research suggests that from 8 years old, children are able to include factual information in constructing their ‘autobiographical memory narratives’ (Pasupathi and Wainryb, 2010). The sophistication of what is included in CYPs’ narratives develops over time and CYPs are able to include interpretative information during the adolescence period (Pasupathi and Wainryb, 2010).
	Children who experience attendance at HS on a regular basis (at least once a fortnight)	It was necessary to have CYPs who had significant experience of HS, in order for them to be able to talk about this experience.
	Children who have longer term stays at hospital due to CCs, e.g. children who receive dialysis treatment and therefore visit hospital regularly for this purpose.	For this study, CYPCCs were the population of interest, as their frequent visits to hospital meant that they would have significant experience of hospital and HS.
	Children who have experienced HS for a minimum of 6 months	6 months was thought to be sufficient time for children to have experienced HS. Less than 6 months was considered insufficient to be able to talk at length about this experience.
Exclusion	Children with SEN (as defined by the SEN Code of Practice (DfES, 2001) with their primary SEN under the categories of communication and interaction; cognition and learning or behaviour, emotional and social development)	It was regarded that children with SEN with their primary needs as noted, were likely to be inhibited with regard to producing rich narratives and may have difficulties in accessing the narrative interview. Tsai and Chang (2008), for example found that CYPs with language difficulties had more difficulties in producing clear and coherent narratives. Compared to children with typical language development, CYPs with language difficulties produced narratives with fewer narrative components, evaluation devices, and connectives, and more ambiguous referencing information was evident in their narratives (Tsai and Chang, 2008). This is supported by substantial research literature (Norbury and Bishop, 2003; Duinmeijer et al., 2012).
	Children with life-threatening conditions	This was primarily an ethical measure to ensure that CYPs and families were not put in a situation where CYPs wanted to participate in the study, but were at a particularly difficult and stressful

	Criteria	Rationale
		time. I considered it unethical to place additional undue stress onto the CYP and their family. This is supported by research literature, for example Board and Ryan-Wenger (2002) who indicate that critically ill CYPs should not be approached for research and their families should not be 'bothered' by researchers due to the nature of their child's illness. Furthermore, James and Curtis (2012) also did not include CYPs who were terminally ill or those with life-threatening illnesses, for ethical reasons.
	Children who are deemed not well enough by medical staff to attend HS, and therefore participate in this research project	This was also an ethical measure to ensure that CYPs' health was prioritised. Furthermore, I wanted to ensure that interviews were carried out in a way that fit in with CYPs' typical HS routine. As such, if CYPs were deemed not well enough to attend HS by medical staff, they were also deemed not well enough to participate in the research.

In addition to the selection criteria outlined in Table 14, participants were asked a few short scaling questions, regarding their emotional and physical wellbeing prior to the interview (Appendix 2). Based on the CYP's responses to these questions, they were only included in the study if I deemed that the interview was appropriate for the CYP at that particular time.

3.8.2. Introducing Suzan

Suzan¹³ told the story of her own experiences in hospital and HS.

¹³ Pseudonyms have been used to represent all participants. Some of these names were chosen by the participants themselves, and if they indicated a preference of name, this was used. Efforts were made for names to be culturally sensitive, if participants did not select a preferred name.

Table 15: Introduction to Suzan

Pen portrait	Information about interview
Suzan is 16 years old and enjoys listening to music and watching horror movies. With regard to school, Suzan likes Maths and Technology, particularly making models. Suzan lives with her Mum, Dad and two siblings (one sister and one brother aged 14 years and 12 years respectively). Suzan also has one older brother who is 33 years old who does not live with her. Suzan told me that her “kidneys are not working very well” and she therefore comes to hospital to receive dialysis treatment ¹⁴ . Suzan currently attends hospital three days a week and HS twice a week, in which a teacher teaches her by her bedside. Suzan told me that she will be transferring to adult care very soon, due to her age. Suzan is Pakistani and has been in England for 8 years. She has received hospital care for approximately 4 of these years.	In the interview, Suzan at first presented as quite shy. However, it was evident that she became increasingly comfortable and accustomed to the interview format as the interview progressed. Suzan appeared to enjoy the interview conversation and attempted to answer all questions, with some prompting.

3.8.3. Introducing Farah

Farah is a 16 year old girl, who told her own story of her experiences in relation to hospitalisation and her attendance at HS.

Table 16: Introduction to Farah

Pen portrait	Information about interview
Farah likes going out to see her friends and family and she enjoys watching movies and going to restaurants. Farah is now at college and she studies hairdressing, which she greatly enjoys. Farah attends college 4 days a week and hospital 3 days a week (for 4 hours each time) for dialysis treatment in relation to what she described as kidney failure cystinosis. Farah lives with her Mum and her younger brother who is 11 years old. Farah told me that she has been coming to hospital since she was 3 years old and has received	During the interview, Farah presented as friendly and cheerful and seemed comfortable speaking about her experiences. However, what was not known prior to the interview was that this was her last day at the children’s hospital, as like Suzan, she would be moving to adult healthcare. As a result, Farah was distracted at times, e.g. distributing sweets to friends on the ward as a ‘leaving

¹⁴ Dialysis is a medical procedure which is used for patients when their kidneys are not working as they should. Dialysis removes waste products and excess fluid from the blood and frequently involves diverting blood to a machine to be cleaned.

hospital schooling since she was 'very young' only when she was well enough intermittently. Since she has been on dialysis, she has received hospital schooling for approximately one year, twice per week.	present' to them. Additionally, she became quite emotional when another patient's mother came to say goodbye to her. Although Farah was given the option of ceasing the interview following this emotional interaction, she chose to continue as it was near the end of the interview at this time.
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3.8.4. Introducing Sumayah

Sumayah is a 16 year old girl in Year 11, who told her own story of her experiences in relation to hospitalisation and her attendance at HS.

Table 17: Introduction to Sumayah

Pen portrait	Information about interview
Sumayah had recently finished her GCSE examinations, which she was pleased about. Sumayah expressed that she enjoys going out, e.g. to the cinemas and enjoys playing on her Xbox, particularly action games. In her family are her Dad, her Mum, her sister (20 years), her brother (18 years), her sister (17 years) and twins who are aged 10 years. Sumayah expressed that she enjoys being in a big family and said that most of the time it is 'warm' and 'comforting'. Sumayah disclosed a complex medical history and told me that at a young age she had cancer, which spread to her kidneys. After the cancer was treated, it then returned to her lungs. Sumayah explained that she had a kidney transplant. For 9 years Sumayah described herself as in fairly good overall health, despite the occasional problem. As a result of medical advice, Sumayah went on peritoneal dialysis (PD) ¹⁵ . However, this was unsuccessful and Sumayah returned to dialysis, which she has now been on for two years and says is working well. Sumayah said that she now receives home	During the interview, Sumayah was polite and open about her experiences. She took a mature approach to story-telling, and I inferred that she had reflected on her experiences previously. I also understood that Sumayah had spoken to adults previously and had been interviewed as part of a TV programme on the children's hospital. In our initial meeting, Sumayah was excited about participating in the research and liked the idea of telling me her 'story'. During the interview, there was one interruption as a nurse came in to invite Sumayah to watch Farah opening presents, as it was her last day at the hospital. I encouraged Sumayah to attend this ceremony as it was clear that the girls were good friends. Sumayah promptly returned to the interview, which was commendable, given the somewhat chaotic context.

¹⁵ PD is one of the two main types of dialysis (haemodialysis being the other one). PD involves the inside lining of the individual's abdomen being used as the filter, rather than an external machine which is used in haemodialysis.

haemodialysis, which means increased independence for her. Sumayah received HS twice a week (for approximately one hour) until recently, in preparation for her GCSE exams, and is going to college next term to study health and social care. Sumayah attends hospital 5 days a week (Monday-Friday) for 4 hours each day.	
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3.8.5. Introducing Rose

Rose is a 12 year old girl in Year 7 who lives outside of the city where the children's hospital is based. She told me about her own story of her experiences in relation to hospitalisation and her attendance at HS.

Table 18: Introduction to Rose

Pen portrait	Information about interview
Rose enjoys arts and crafts activities such as drawing and painting. Rose's passion is dance and she was an avid dancer prior to her ill-health, e.g. entering local competitions. In Rose's family are her Mum, her grandparents, uncles, aunts and cousins. Rose lives with her Mum at home and has a close relationship with her grandparents, who she sees daily. At school, Rose's favourite subjects are textiles, music, art, and German. Rose stated that she first became 'poorly' with cancer when she was 9 years old and received chemotherapy for two and a half years. Rose said that she relapsed and now has cancer again - she has a diagnosis of acute lymphoblastic leukaemia ¹⁶ . Rose has experienced hospitalisation and HS at two different hospitals.	Rose engaged very well with the interview process and presented as an intelligent and open girl. Rose's Mum was in hospital on the day of the interview and on occasion joined in with the interview, sometimes offering her points of view.

3.8.6. Introducing Sajid

Sajid is a teenage boy who told me about his experiences of hospitalisation and HS, with additional support from his mother who was present throughout the interview.

¹⁶ This is a type of cancer which affects the white blood cells and requires immediate treatment due to the rapid progression of the illness.

Table 19: Introduction to Sajid

Pen portrait	Information about interview
Sajid is 13 years old and is in Year 8. He attends mainstream school in addition to HS and has experienced HS in two different hospitals. Sajid also experienced home education when he was primary school age. Sajid has a diagnosis of severe combined immune deficiency ¹⁷ and will require a bone marrow transplant. Sajid likes watching TV programmes such as Top Gear, enjoying the comedic and driving aspects of the show. Sajid also likes playing on the Xbox, in particular war-related games. At school, Sajid's favourite lesson is Science because he likes to do experiments and he also enjoys Drama. Sajid lives with his Mum, Dad and two younger siblings (one brother and one sister).	Sajid was keen to participate in the research and expressed as such. When I first visited Sajid for interviewing, he was required to undergo a surgical procedure which had unexpectedly been brought forward. Sajid's mother asked if I could come the following day, which I did. During the interview, it was easy to build rapport with Sajid and in some ways he quickly became very familiar with me.

3.9. Interview contexts

Gergen (2004) indicates that narratives are co-constructed within a context and are shaped by a number of interacting factors such as the identity of the interviewer, the questions posed and the temporal-spatial characteristics of the interview. The context of an interview, including the physical surroundings, how the interviewee feels on the day of the interview and what other concerns are pre-occupying them (Andrews, 2008), may impact on the data collected. Furthermore, transparency must be upheld regarding narrative interview contexts so that readers can evaluate data analysis (Holloway and Jefferson, 2013) and research quality (Creswell, 2013). Further to this, Daiute (2004) adds that contextual information is critical when considering narratives in order to provide a fuller and more accurate picture of how CYPs perceive the world around them.

¹⁷ This is a rare inherited disease which causes significant difficulties in the immune system, as a result of white blood cells missing or working incorrectly.

All interviews were conducted in a variety of settings, for example on the wards (each of which varied considerably in terms of noise and privacy levels), by the CYPs' bedsides and in a separate 'young people's room'. The interviews were subject to several interruptions, for example by healthcare professionals, which is not uncommon for social research in hospital settings (Coyne et al., 2009). The organisational context of busy hospital wards can greatly influence successful data collection and also in this case, the production of fluent and uninterrupted narratives. Furthermore, the hospital environment is not an ideal environment for research (Coyne et al., 2009), for example with issues concerning privacy and confidentiality (see Section 6.5.2). For further information about interview contexts in the present study refer to Appendix 7.

3.10. Reflexivity

Reflexivity refers to an increased awareness of the self and identity in research (Elliott, 2005). Squire et al. (2008, p. 17) posit that "we as narrative researchers are crucially a part of the data we collect; our presence is imprinted upon all that we do". The narrative approach requires that the researcher's 'positioning', on which research is based must be acknowledged, which this section seeks to address.

I argue that reflexivity is at the heart of narrative research, given the nature of this type of research. Elliot (2005) suggests that once it is illuminated that participants provide narratives which are not simply reports of their experiences, but rather are a result of a

sense-making activity, narrative researchers too are obliged to recognise that their own research narratives are also constructed.

The importance of reflexivity is not only in respect to data collection, but also for data analysis, interpretations drawn in the study, and the way in which research evidence is presented (Elliott, 2005). Furthermore, explicit researcher reflexivity has positive implications regarding evaluation of the quality and scholarship of research (Creswell, 2013). Researchers should not only convey their experiences relating to the phenomenon under investigation, but also indicate how these personal experiences shape the findings, conclusions and interpretations drawn in the study (Creswell, 2013). Moreover, readers have a 'right' to know about the researcher (Wolcott, 2010). To this end, it is important to firstly acknowledge my own extensive experience of hospitalisation, although this has been as an adult and not during childhood or adolescence. I recognise that my personal experience of hospital in addition to my personal and professional values of listening to the voices of children, social justice, social inclusion and elevating the voices of the underrepresented in research, influence the data generation process. Salmon and Reissman (2008) indicate that an individual's personal account in a research interview is in reality always a co-construction as the narrative emerges from this joint encounter. As a TEP with the aforementioned background and interests, I was especially interested and attentive regarding the participants' stories and demonstrated this explicitly using both verbal and non-verbal indicators (Section 3.6.5 details the interview process). Having something in common with the CYPs, although this was unknown to them, meant that my levels of attunement and empathy were high which may have impacted the co-construction of

narratives and the interviewee-interviewer relationship. My own feelings during the interview in response to the hospital environment and the CYPCCs' stories may also have inadvertently and subtly influenced the co-construction of the narratives.

Furthermore, I acknowledge my influence on data analysis, interpretation of findings and conclusions drawn. I use the first person throughout the research to emphasise that the results and interpretation of narratives are inherently subject to my own influence. Elliott (2005) indicates that the researcher acts as a narrator in interpreting others' narratives.

3.11. Ethical considerations

Deliberation of ethical issues was prioritised for this research, particularly with reference to the following professional guidelines: BPS Code of Ethics and Conduct (2009), BPS Code of Human Research Ethics (2010) and BERA Ethical Guidelines for Educational Research (2011). As research protocol dictates, I sought and gained ethical approval from relevant ethics committees prior to participant recruitment and data collection. NHS ethical approval was sought¹⁸ and a favourable ethical opinion for the study was obtained from the local research ethics committee (Wales REC 4) in November 2014 (Appendix 8) and May 2015 (Appendix 9) following amendments made to selection criteria (Appendix 10)¹⁹. Approval was also obtained in January 2015 from the relevant NHS Foundation Trust research and development directorate (Appendix 11).

¹⁸ NHS ethical approval was sought due to the research project involving NHS in-patients as participants.

¹⁹ Amendments were made to the selection criteria (see Appendix 10) as a result of meeting with HS staff and the clinical lead. This meant that ethical approval needed to be sought once more, despite approval in December 2014. Approval of amendments on 29th May 2015 meant that I was able to commence data collection on 16th June 2015.

The key ethical issues considered for this study are outlined in Table 20. This not only accounts for the many ethical issues faced generally by qualitative researchers (Creswell, 2013), but also issues specific to this type of research, the nature of which diverges from the norm, involving the hospital context and in-patients.

Table 20: Key ethical issues involved in the present study and measures taken to address these issues

Ethical issues	Measures taken to address ethical issues in the present study
<i>Identifying, approaching and recruiting participants</i>	<ul style="list-style-type: none"> ○ The Head teacher of the HS and the Clinical Lead acted as gatekeepers for the research, distributing information sheets to the parents/carers of eligible CYPCCs. The recruitment of participants is further detailed in Section 3.8.1.
<i>Informed Consent</i>	<ul style="list-style-type: none"> ○ Parents/carers of children who were eligible to participate in the research were asked to provide written consent (Appendix 12), after having received written information about the research project (Appendix 5) and having been given the opportunity to meet with myself and/or discuss concerns or questions about the research project. ○ I met with pupils with parental permission on an individual basis for the purpose of orally explaining the research to them and asking for voluntary participation. Pupils were also provided with written information about the research project for their own reference (Appendix 5) (BERA, 2011). This meeting provided an opportunity for potential participants to ask questions about the research. Once questions were answered and CYPs reported understanding of the information, they were asked to complete a separate consent form (Appendix 12) (BPS, 2009; BERA, 2011). The consent form asked pupils if they had understood the research project information and whether they gave their consent to participate.
<i>Participants' right to withdraw</i>	<ul style="list-style-type: none"> ○ Participants' right to withdraw was explained both on parents' information sheets and CYPs' information sheets (Appendix 5). Furthermore, participants' right to withdraw was explained verbally to each participant, both in the meeting prior to the interview and in the interview itself, to ensure that this was clearly understood by the CYP. ○ Prior to and during the interview, participants were free to withdraw at any time. Following the interview participants were given a period of 7 days to withdraw from the research. ○ It was specifically detailed to participants (and parents where necessary) that it may not be possible to eradicate some information e.g. specific comments from the audiotaped recording, although it would be possible to remove these from the written transcripts.
<i>Confidentiality</i>	<ul style="list-style-type: none"> ○ During my meetings with participants, transparency was ensured regarding the limits of confidentiality and issues surrounding confidentiality, for example specific unique aspects of their stories which may reveal their identity to people who know them well. Participants were told that every effort would be made to

Ethical issues	Measures taken to address ethical issues in the present study
	<p>ensure that such identifying details were not reported in cases where the audience members are likely to be able to decipher the participant's identity by unique aspects of the story, for example in the feedback report to the HS.</p> <ul style="list-style-type: none"> ○ Participants (CYPs) and their parents were informed of issues concerning confidentiality prior to interviews taking place, on their respective information sheets and consent forms. ○ Pseudonyms were used throughout the interview transcripts and reports, instead of real names.
<p><i>Risk of 'harm' – emotional distress for participants</i></p>	<ul style="list-style-type: none"> ○ Selection criteria excluded CYPs with 'life-threatening' medical conditions (see Section 3.8.1 for inclusion and exclusion criteria). Furthermore, CYPs with SEN (as defined by the SEN Code of Practice, DfES, 2001) with their primary SEN under the category of behaviour, emotional and social development were excluded from the study. ○ Participants were invited to have their parents/carers present with them during the interview, if this helped them to feel more comfortable during the interview process. ○ I arranged to meet participants prior to the interview to build rapport with the CYPs and answer any questions they had regarding the research. Coyne et al. (2009) suggest that meeting hospitalised CYPs before an interview is crucial not only for building rapport but lessening potential anxieties they may have about the process. ○ Participants were told that the interview could take place over more than one session, in the event that the participant felt tired and needed to rest or other such eventualities. ○ Only if the CYP was deemed well enough to attend HS by hospital clinical staff could the interview take place on that day. ○ The study involved the use of a 'Clinical Lead' (clinical team member) to oversee procedures such as the recruitment of participants and to ensure participants' fitness to participate in the study. ○ Participants were asked a few short and informal questions regarding their wellbeing (both emotional and physical) prior to the interview taking place to determine whether an interview was appropriate for the CYP at that time using scaling questions. Based on CYPs' responses to these questions, I decided whether the interview was appropriate for the CYP at that particular time. ○ As a TEP, with part of my training involving therapeutic and counselling skills, I was well-placed to conduct the narrative interview with sensitivity, empathy and attunement. Furthermore, my vast experience in

Ethical issues	Measures taken to address ethical issues in the present study
	<p>working with CYPs meant that I was able to build a rapport quickly with the CYPs and was able to read the interview situation well and tune into the emotional needs of the CYPs.</p> <ul style="list-style-type: none"> ○ The use of a narrative interview was in itself a vital part of reducing the likelihood of harm to participants as literature suggests that narrating about personal experiences can have a direct, therapeutic benefit for research participants (Murray, 2008). ○ In the event of participants becoming visibly distressed, it was planned that participants would be reminded that they did not have to answer the particular question or could move on from the topic causing distress. Participants were also reminded that they could take a break/pause the interview if they wanted or terminate the interview entirely and withdraw if they wanted to. ○ A designated member of staff from the HS was identified, in the event that participants needed support or after care following an interview. Fortunately, this resource did not have to be used. ○ All participants were asked how they felt at the end of the interview in order to provide them with a debriefing opportunity to reflect on their emotions during and after the interview (See Appendix 2 for full interview guide)
<i>Risk of harm to myself as researcher</i>	<ul style="list-style-type: none"> ○ I anticipated that there would be a risk to myself as researcher in carrying out this research study, particularly during data collection and data analysis stages. I therefore took measures to protect my own wellbeing as researcher during the data collection and analytic procedures. I engaged in self-reflection and sought peer supervision in order to address my cognitive and emotional responses in addition to taking breaks as necessary, during the analytic process and following each interview. I also maintained a log of my emotional responses to aid self-reflection and ultimately reduce the risk to myself as researcher.
<i>Storage, access and disposal of data</i>	<ul style="list-style-type: none"> ○ All data was kept and stored in accordance with the Data Protection Act (1998, modified 2003). ○ Interviews were recorded using a storage device and then transcribed (with no names/personal details). After each interview, electronically audio-recorded data was removed to a password-protected and encrypted computer file that only I, as researcher, had access to. The audio files were then deleted from the audio-recorder. Written field notes taken during the interview in situ were stored in a locked filing cabinet. Any printed transcripts were also stored in a locked cabinet which only I had access to. Participant names were only included on consent forms which were kept in a locked filing cabinet also. ○ Written notes were not attributed to individuals but were identified by codes/pseudonyms. Transcription

Ethical issues	Measures taken to address ethical issues in the present study
	<p>data was stored on a password protected laptop/memory stick. Only myself as researcher had access to this.</p> <ul style="list-style-type: none"> ○ In line with university ethical guidelines, all data (electronic recordings, field notes and typed transcripts) will be kept for 10 years on a password-protected memory stick, during which time my supervisor and I and relevant individuals from the University of Birmingham may have access to it. After this time, all electronic data will be erased (and removed from any back-up drives) and printed interview transcripts securely shredded.
<i>Transcription, analysis and reporting of data - respect for narratives</i>	<ul style="list-style-type: none"> ○ The transcription, analysis and reporting of narratives involved a high consideration of respect in order to represent the stories of CYPs in the most accurate and ethical way. I remained fully aware that in reality, these narratives were given to me as a 'gift' (Horsdal, 2012) and were not mine to disrespect or treat with disrepute. In fact, it was an honour and privilege to be given these narratives and they should be treated accordingly. It was anticipated that narratives would be verified by participants ('member/respondent checking'), as recommended in literature (Webster and Mertova, 2007; Reissman, 2008; Creswell, 2013) but this was not possible for practical reasons. As Reissman (2008) acknowledges may happen, considerable time passed between my interviews and full data analysis. This meant that the vast majority of participants had been discharged from the hospital or transferred to adult care when it came to the appropriate time for member checking to take place.
<i>Feedback to participants and stakeholders and dissemination of findings</i>	<ul style="list-style-type: none"> ○ In recognising my ethical duty to share the findings of this research to influence improved practice, a research summary will be provided for staff at the HS in which the research took place. Moreover, it is anticipated that the findings will be shared further as the HS has positive links with other HSs nationally. ○ A research summary will also be shared with the Educational Psychology Service (EPS) at which I was placed as a TEP during the progression of this research. ○ Feedback letters will be distributed to participants. These will be sent to the CYPs via the HS due to the large proportion of participants who no longer attend the HS since the research took place. Many participants for example, have been discharged or transferred to adult care. ○ Findings from the current research may be shared via professional research journals, to improve awareness on the research topic and to influence professional practice.

Significant ethical challenges were faced as a result of the nature of the research. Reflections on these challenges and how the data collection process was significantly hampered are discussed in Section 6.5.2.

3.12. Data analysis

3.12.1. Transcription

I chose to transcribe the audio-taped interview recordings myself (see Appendix 13 for exemplar transcript). Transcription is not universal to qualitative (or narrative) research (Horsdal, 2012), and is challenging, not only because it is time-consuming, but it also requires a careful negotiation of translating dynamic interactive dialogue into linear written language, in which many of the subtleties of the interaction are lost (Reissman, 2008). However, I deemed transcription not only necessary, but critical to the analytic process (Wengraf, 2001; Elliott, 2005).

As suggested by Elliott (2005), I created somewhat ‘clean transcripts’, which excludes non-lexical utterances such as ‘umm’ and ‘err’, as well as repetition and false starts. However, intonation was noted in the transcripts when deemed appropriate, for example when something was said in an excited way or with added emphasis. Substantial pauses were also noted. Producing somewhat clean transcripts was beneficial for enabling the focus to remain on the *content* of what was said (Elliott, 2005), which is the primary focus of this research, rather than the function of the narrative and the narratives’ ‘performative’ qualities. Elliott (2005) proposes that sanitisation of transcripts enables the chronology of events as well as the evaluative elements of the narrator to be captured.

I chose not to omit my own voice in the transcriptions, which is an option for narrative researchers (Elliott, 2005). I included my words in order to emphasise my role in the co-construction and meaning-making in the narrative process (Reissman, 2008). As Polkinghorne (1988) indicates, explicit transcription rules and a well-specified notation system should be devised to enhance the trustworthiness of the research (Section 3.7.1 identifies measures taken to ensure trustworthiness in the present study). I therefore established a notation system used in the transcription stage of data analysis, which is outlined in Appendix 14. At the beginning of each transcript, a brief description of the interview context (e.g. setting and time) was provided.

3.12.2. Data analysis procedures

Elliott (2005, p. 37) states that “there is no single narrative method, but rather a multitude of different ways in which researchers can engage with the narrative properties of the data”. Indeed, Reissman (2008, p. 11) posits that narrative analysis refers to a ‘family of methods’, which although adds complexity is in fact a key strength of narrative analysis (Daiute and Lightfoot, 2004). As there are a range of accepted approaches already used in methodological literature, I decided to apply a combination of approaches, i.e. a bespoke eclectic approach to analysing these data, in line with the fundamental ideas and underpinnings of narrative research, my own epistemological commitments and the

particular RQs of this study. This analytic process, including transcription, is detailed as a flow chart for ease of reference (see Figure 1)²⁰.

Squire et al. (2013) make an important distinction between ‘event-centred’ and ‘experience-centred’ narratives, which has guided my data analysis decisions. In focusing on the experiences of hospitalised CYPCCs, my RQs inevitably relate *both* to particular events that have happened to the individual (event-centred) as well as a specific emphasis on the individual’s thoughts and feelings about the events (experience-centred) (Squire et al., 2013). Furthermore, Labov and Waletzky (1967) argue that fully formed narratives contain certain components, including a ‘complicating action’ (the events i.e. what actually happened) and the evaluation (what the event means to the narrator) (Elliott, 2005), which directly relate to my RQs. Each story was analysed separately, to demonstrate appreciation of each story’s uniqueness and complexity in addition to taking advantage of narrative analysis’ opportunity for exploring people’s lives holistically (Daiute and Lightfoot, 2004).

In maintaining transparency, I claim that the data analysis process was both inductive and deductive. As Polkinghorne (1995) states, qualitative analysis is closely aligned with inductive analysis, i.e. conclusions are data-driven. However, my influence as researcher is inevitable, not only in terms of my own positioning (e.g. my epistemological view and life experience), but also by my understanding of the topic through reviewing relevant literature. It is thus unavoidable that the lens through which I interpret the data, is

²⁰ Note: This model is a simplification of the data analysis procedures, for ease of conceptualisation for the reader. Procedures are not necessarily linear, but rather dynamic and flexible. Self-reflection, interpretation, note-taking, revising and refining of narratives occurred throughout the data analysis process.

influenced by existing research and theory and is therefore also a deductive process. I acknowledge the *ethical dimension* in analysis relating to narrative data, due to its inherently reflective nature (Daiute and Lightfoot, 2004) and the need to exercise sensitivity when deconstructing and interpreting narratives (Elliott, 2005), a point often unrecognised in other social science research (Daiute and Lightfoot, 2004).

The data analysis process consisted of four key analytic phases, as depicted in Figure 1, namely i) summarising the individual narratives, ii) restorying of the narratives iii) thematic analysis and iv) holistic analysis of the narratives. Explanations and rationales for each of these four analytic phases are explained in Section 3.12.3.

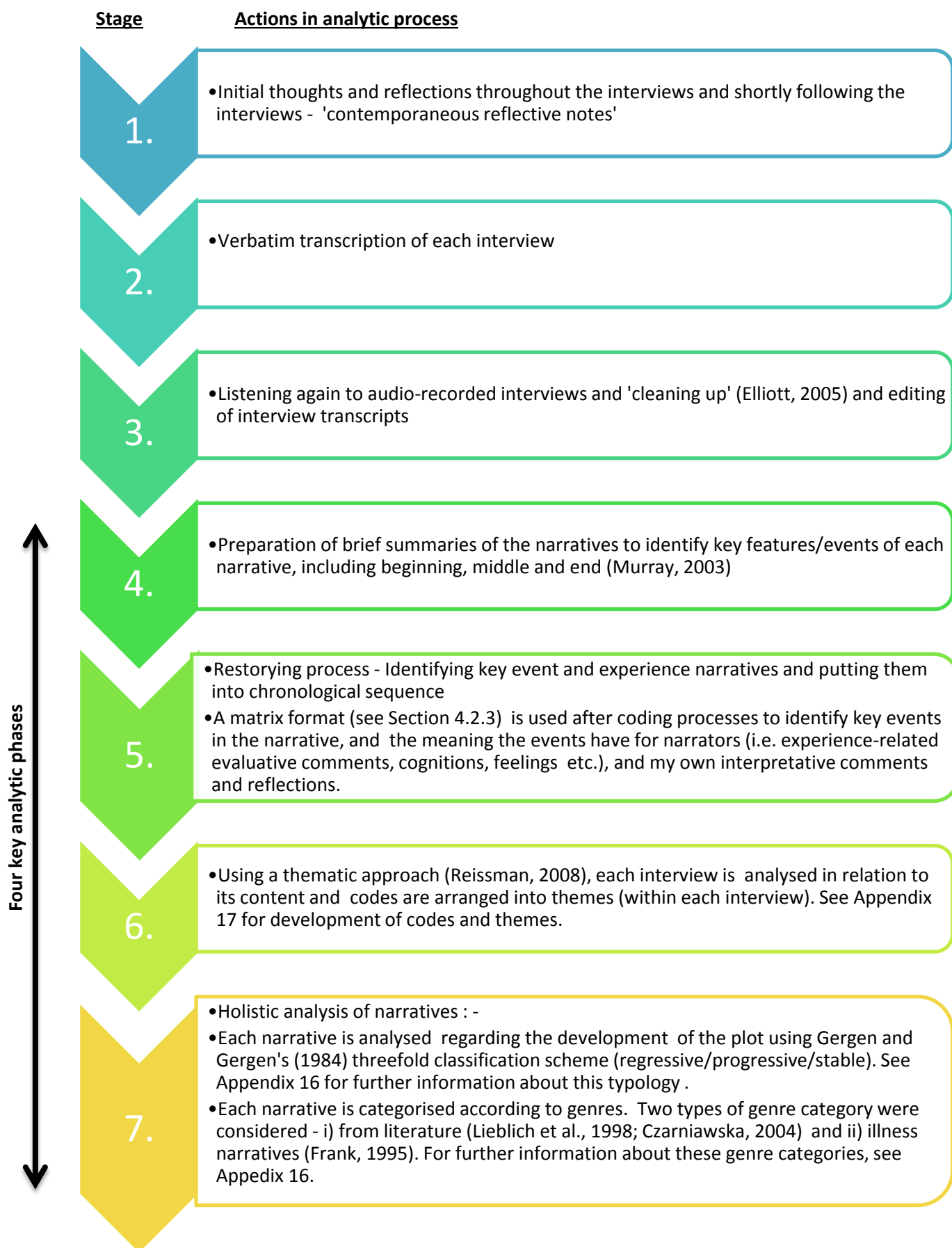


Figure 1: Data analysis procedures used in the current study

3.12.3. Explanations and rationales for each analytic phase during data analysis procedures

3.12.3.1. Narrative summaries

Murray (2003) emphasises the importance of researchers summarising narratives at the initial stages of the analytic process in order to become familiar with the different narratives. This summarising process involves briefly summarising the whole narrative, including key features, events and happenings, as part of the identification of a beginning, middle and end (Murray, 2003) which is a key feature of narratives. I elected to devise a separate summary for each individual narrative account in accordance with my commitment to preserve the wholeness and uniqueness of each individual narrative.

3.12.3.2. Restorying of narratives

Firstly, events that CYPCCs reported to have happened whilst they have been hospital patients and attended HS were identified. A process loosely based on Polkinghorne's (1995) 'emplotment' of events was adopted to identify events, because the aim of this type of analysis is the generation of a story, which was my aim also. However, only some elements of this framework were utilised and not others, as these related to the explanatory dimension of the framework; i.e. how and why something occurred, which is unsuitable and unrelated to my descriptive RQs. I use the term 'restorying' rather than 'emplotment' to make the distinction clear. My focus was on configuring event elements (parts) to a coherent storied narrative (whole), in order to explore CYPCCs' experiences of these events,

although this was undertaken in a descriptive way, rather than for explanatory purposes. The process of restorying occurred following the initial coding of event-centred comments (see Appendix 15).

Occurring simultaneously and alongside the identification of key events that had reportedly happened to hospitalised CYPCCs, was the analysis of how CYPCCs perceived these events. Evaluative elements are what convert a simple account of events into a true narrative (Elliott, 2005) as evaluation is indicative of the meaning and significance events have for the narrator. In this study, the RQs are primarily concerned with evaluative elements in the narratives, in order to understand how CYPCCs make sense of their social world, as well as facilitating the process of empathising with the research participants (Elliott, 2005).

In sum, the aim of the restorying process was to attain rich understandings of CYPCCs' experiences of hospital and HS in relation to significant events. During my analysis, I particularly attended to narrators' evaluations of experiences in terms of their emotions and cognitions about their experiences (Squire et al., 2013). Elliott (2005) argues that narrators' evaluations can be provided via 'explicit' evaluative statements or embedded in the narratives i.e. implicit. To this end, explicit evaluative comments made by participants were identified and interpreted, in addition to linguistic devices (e.g. repetition, emotive language) and also clear non-language indicators, such as laughing. A matrix format was used to identify and organise CYPCCs' reported key events during their time at hospital and HS (event-centred narrative), the narrators' evaluations of their experiences (experience-centred narrative) in addition to my own interpretations and evaluative comments. My

restorying of participants' narratives is not a 'neutral representation of the research finding' (Polkinghorne, 1995, p. 19), but rather a product of my own constructions which have shaped the conclusions.

3.12.3.3. Thematic analysis

A thematic approach was judged appropriate following the restorying process in order to identify key themes in relation to participants' experiences of hospital and HS and the meanings and significance of these experiences. Reissman (2008) identifies four ways to analyse narrative data, one of which she terms 'thematic analysis', which can be used singularly or in combination with other approaches, to address the researcher's aims and interests. Thematic analysis, which is the most common approach to narrative analysis (Reissman, 2008), is suitable when researchers are interested in what is spoken during interviews, rather than, for example, how the story is told. This is the case for the present study. This approach is also included in Mishler's (1995) typology of analytic strategies, which includes analysing the content and meaning of narratives. Mishler (1995) indicates that some researchers are primarily interested in the actual events and experiences that are recounted in the narratives, as is the case for the present study. The 'content' of a narrative is not only a chronological description of past events, but also entails evaluative functioning (Mishler, 1995), which is associated with the RQs.

Polkinghorne (1995) discriminates between 'narrative analysis' and 'analysis of narrative', the latter of which has been used to analyse data for the present study. 'Analysis of narrative' seeks to 'locate common themes or conceptual manifestations among the stories told as data' (Polkinghorne, 1995, p. 13). Although Polkinghorne (1995) identifies the commonality of researchers investigating different stories to illuminate which themes occur across the stories, this has not been employed for the present study as I sought to keep the stories intact, and to identify themes within each individual, unique story.

3.12.3.4. Holistic analysis

The final analytic phase involved the holistic analysis of each narrative. Holistic analysis of narratives attempts to understand parts of the text in the context of other parts of the narrative, in contrast to categorical analysis which does not seek to preserve the integrity of the whole accounts and lends itself to traditional content analysis and statistical methods of analysis (Elliott, 2005).

Firstly, as part of the holistic approach, Gergen and Gergen's (1984) threefold classification scheme was adopted. Following the representation of the five cohesive narratives, each narrative was holistically analysed focusing on the dynamics of the plot over time. Gergen and Gergen's (1984) terminology of 'regressive', 'progressive' or 'stable' narratives, was assumed (see Appendix 16). This particular aspect of the analysis was based on the identified key events in addition to narrators' and my own evaluations of events. Gergen and Gergen's temporal model is not only useful for organising material (Murray, 2003) but

allows for the development of the plot to be analysed in greater detail. Furthermore, this type of characterisation of narrative accounts is useful to explore the connections placed in narratives, as well as an exploration of the different narrative identities constructed in the narratives (Murray, 2003).

Secondly, an holistic analysis of each narrative was conducted in relation to categorisation of narratives using a typology or literary genre (Lieblich et al., 1998). Genres can be from literature (e.g. comedy, tragedy, romance), film (e.g. horror) (Elliot, 2005) or from contemporary society (Squire, 1999). In the present research, I used two different types of genre, drawn from a literary perspective (Lieblich et al., 1998; Czarniawska, 2004) and an illness narrative perspective (Frank, 1995). For further information about the use of these two genres, see Appendix 16. The use of 'genre' as an analytic tool was considered important to explore the form of the narratives at a surface level, which was of interest to me. Moreover, genre not only brings the heart of the story to the fore but it also provides a culturally shared framework to structure experiences in a meaningful and easily communicable way (Elliott, 2005). It was also anticipated that genres would facilitate theorising processes.

4.0. FINDINGS

4.1. Chapter overview

This chapter presents the findings of the current research: my interpretations of narratives from hospitalised CYPCCs concerning their experiences of hospital and HS. I discuss the findings in full for one participant, Sumayah, who is used as an exemplar to demonstrate the interpretative process, due to the unanticipated wealth and depth of data. Full narratives and interpretations in relation to the other four participants - Suzan, Farah, Rose and Sajid - are presented in full in Appendix 19, in line with my commitment to holding the participants' voices in the highest esteem and not prioritising one voice above the others. I selected Sumayah as the exemplar because she provided a rich and in-depth narrative, which I therefore judged would be a good example to illustrate the analytic process in a rich and comprehensive way. Each of the five participants (see Section 3.8 for pen portraits) were analysed in turn, in line with my commitment to keeping the stories of participants individual and separate. The interview context is also reiterated so that the analysis of data is firmly grounded within a specific and unique context, to heighten the quality of the analytic process (Yardley, 2000; Polkinghorne, 2007; Reissman, 2008). I also judged it important to reflect on my own experience of analysis, in adhering to my commitment to reflexivity for heightening the quality of my research (Reissman, 2008; Creswell, 2013). I acknowledge that the analytic process was at times emotional, which may influence my interpretations, and I judge it not only imperative to demonstrate self-awareness of this, but also self-exposure for the readers' sake. This serves to acknowledge my own agency in the interpretation of findings and that the voice through which the findings are depicted is my own.

In this section I systematically detail findings from Sumayah's narrative in relation to the four main stages of data analysis, as outlined in Section 3.12.2, i.e. i) narrative summary, ii) narrative restorying iii) thematic analysis and iv) holistic analysis, in order to address the RQs. I begin the representation of findings with the holistic aspect of analysis, to outline the development of the narrative as a whole, before analysing the narrative in its parts. Direct quotations and segments of the original transcript text are used not only to evidence my interpretations, but also to hold the participants' own words in the highest esteem.

4.2. Sumayah

Sumayah's interview took place in the afternoon and as she had finished her dialysis, she suggested the 'young people's room' as the interview location. This small room was away from the wards, with entertainment for CYPs, such as books, games, a TV and an Xbox. There were three chairs in the room, and Sumayah and I sat on two of them, sitting adjacent to each other. Whilst analysing Sumayah's interview, it is important for transparency purposes to acknowledge the impact this process had on me as the researcher. I had some strong emotional reactions during the analysis of Sumayah's interview, particularly as a result of my own researcher positioning as a person with extensive (and often negative) experiences of hospitalisation. At times I experienced strong emotions in response to Sumayah's tone of voice which was sometimes quite melancholy, which also made me feel low as a result. There were also at times undertones of Sumayah attributing some things to an internal locus of control. When talking about the inevitability of her kidney not lasting forever, phrases such as "me being me" made me feel uncomfortable as she seemed to view some things as just a part of her life, which may suggest elements of blame, guilt or

resignation in her perceptions of some events. Having personally experienced some of these emotions in my own illness- and hospital-related experiences, I could particularly relate to and empathise with such feelings, and felt sad that Sumayah was experiencing these emotions, especially at such a young age. Furthermore, as a researcher who is also a TEP and regularly works directly with CYPs, it was difficult to listen to a CYP, being in my view, overly hard on herself. I also had a strong emotional response when Sumayah described having pneumonia, her worst moment in hospital. I felt helpless and sometimes even guilty having asked about her worst moment. However, I reflected that although I felt sad and at times guilty, giving these CYPs a *voice* and a platform on which to express their experiences aloud and process them was empowering and positive.

4.2.1. Holistic Analysis

Table 21: Holistic analysis in relation to Sumayah's narrative

	Researcher classification	Researcher Interpretation
Progression of plot (Gergen & Gergen, 1984)	Progressive → Regressive → Progressive	In terms of narrative structure and development, I interpret Sumayah's narrative to be a complex combination of progressive and regressive narratives. Specifically, over the course of Sumayah's experience of hospital and HS, her narrative begins as <u>progressive</u> during her formative years. Sumayah described starting school which was fun and care-free in addition to receiving a life-changing kidney transplant, which significantly improved her life. However, the narrative then becomes <u>regressive</u> , when Sumayah experienced health difficulties and was faced with the reality of the impermanence of her kidney and the implications of this, which was shocking and upsetting for her. I interpret the final part of Sumayah's narrative to be <u>progressive</u> , in which Sumayah describes several positive experiences, such as being helped by HS teachers with her examination preparation, going to London for the first time and receiving an Xbox and a quad bike from her family. Sumayah reflected

		that her life, despite its challenges, has been enjoyable.
Genre of narrative: 1. Literary (Lieblich et al., 1998; Czarniawska, 2004) 2. Illness narrative (Frank, 1995)	1. Comedy 2. Restitution narrative	I deem Sumayah's narrative to be akin to a comedy genre, because although there are several complications in her narrative, particularly regarding her health, Sumayah is currently in relatively good health and is optimistic about the future, thus suggesting a somewhat 'happy ending'. I also consider Sumayah's narrative to be a restitution illness narrative. Although Sumayah has been unwell for the majority of her life, after her kidney transplant she was no longer ill to the same extent as she had been before (and has been since) and the transplant was life-changing to her quality of life. I interpret that although Sumayah reflects on her life as being enjoyable, she ultimately aims to receive another kidney transplant and thus return to a life without the challenges of ill-health.

Sumayah's narrative is characterised by 'ups and downs' in terms of her health and the way she perceives significant life events during her experience of hospital and HS.

4.2.2. Narrative Summary

Table 22 below details the narrative summary in relation to Sumayah's experiences of hospital and HS. It is to be noted that this is my interpretation of Sumayah's narrative and I have selected the key events for the 'beginning', 'middle' and 'end', rather than Sumayah herself. It is therefore reiterated that it is my voice as researcher, which is predominant in the narrative summary. Producing a narrative summary for each of the participants, including Sumayah, was useful for me in terms of becoming immersed in the narratives and gaining an in-depth understanding of each individual story, including their unique features.

Table 22: Narrative summary of Sumayah's experiences of hospital and hospital school

	Interpretation
<i>Beginning</i>	Sumayah first came to hospital when she was approximately one year old. Her early years at the hospital up until the age of 6 years are described in very positive terms. Sumayah explained that at this time she did not understand much about her condition and was somewhat care-free, enjoying life and having 'fun'. Sumayah describes starting school in Reception, which was a significant and positive time for her. In the hospital context, Sumayah was on dialysis at this young age and described learning experiences in hospital, such as playing on the computer and learning about objects and shapes.
<i>Middle</i>	When Sumayah was 6 years old, she had a kidney transplant, after which she enjoyed being more active, for example playing with her brother at the park and eating and drinking as she pleased. However, at this time Sumayah was also informed that her kidney would not last forever, which was disappointing for her. Sumayah described seeing HS for the first time at aged 10 and her delight at its physical appearance, the friendliness of the staff and meeting other children from different wards. Sumayah explained that in 2011 she had pneumonia which she regarded as her worst experience in hospital.
<i>End</i>	Since the age of 14, Sumayah detailed many positive experiences, such as receiving an Xbox and a quad bike from her family, and going to London for the first time with hospital staff and other children on her ward. She also described going to the secondary school unit of the HS, which she stated was different to the primary school, and adopted approaches which were well-suited to her and beneficial to her exam preparation. Sumayah is currently on home haemodialysis treatment and is proud to be one of the first on this treatment.

4.2.3. Narrative Restorying

Table 23 below outlines the interpretative process of restorying Sumayah's narrative. The chapters identified by Sumayah in the interview are used as a framework for her key events and experiences. Exemplary quotations are included in addition to my own interpretative comments.

Table 23: Sumayah's event and experience-centred narrative with additional researcher interpretation and commentary

"The Roller-Coaster of the Odd Life"²¹			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
Chapter 1: 1 year – 6 years	Sumayah first went to Reception	<ul style="list-style-type: none"> “It was a place where a kid my age could well be a kid my age. You know you could play with toys, you could go outside... could go to the library” “I could be me and not need to worry about anything, just have fun.” 	Sumayah remembers starting Reception fondly, as a place where a <u>4 year old child could simply be a child</u> . She describes Reception in terms of activities and <u>having fun</u> . I interpret Sumayah to be looking back at a somewhat <u>simpler time</u> when she was just able to be and play, without having to worry about things.
	Sumayah used the hospital computer	<ul style="list-style-type: none"> “They used to help us read books on there and there used to be this Thomas the Tank Engine clean him game” 	Playing on a HS computer was important for Sumayah, which is again representative of Sumayah's perception that her formative years were a time of happiness, being a child and having fun.
Chapter 2 : 6 to 14 years	Sumayah received a kidney transplant, 5 years after being on dialysis and 3 months after being on the kidney transplant list (*best moment*)	<ul style="list-style-type: none"> “It means having a life” “Being able to eat what you want, drink what you want not be told to stop drinking” “Your life didn't revolve around the hospital” “Because I could really just go out and be more active and have more of a social life” “I was happy, glad, over the moon, had a life.” 	Sumayah identified receiving a kidney transplant as the best moment during her experience of hospital and HS. The transplant significantly impacted her <u>wellbeing and quality of life</u> . I interpret a sense of <u>liberation from restriction and illness</u> , when compared to dialysis treatment. The transplant also meant that Sumayah had more freedom regarding what she <u>consumes</u> and her <u>social life</u> , for example being more active and going out. Upon reflection, Sumayah realised that ‘there's more to that’ and enjoyed spending time with her brother, e.g. running and bike riding. I interpret an element of sadness for Sumayah that she can no longer do those things that

²¹ This title was given by Sumayah. This was in response to my interview question inviting her to think of a title for her story, relating to the story being akin to a book or a film.

“The Roller-Coaster of the Odd Life” ²¹			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
			brought her so much enjoyment. Perhaps she is implying that one should do as much as possible to care for the kidney so that the enjoyment can be maintained.
	Sumayah stayed in hospital for two or three weeks to undergo the kidney transplant procedure	<ul style="list-style-type: none"> • “I used to have this thought when the door was closed and the curtains were drawn that everyone outside is playing catch in the corridor” • “I received loads of gifts from everyone I remember having loads of teddies” • “The painful parts like when they took out my drain. I cried so much that day. It was <i>really</i> painful... they use like a sharp point thing and they took out the stitches and they <i>pulled</i> it and just the thought of it makes you feel sick” 	Although Sumayah did not fully understand (aged six) that she was having a kidney transplant and the implications of this, Sumayah recalled staying in hospital for weeks following the procedure. Sumayah remembered thinking about others playing which perhaps indicates feelings of <u>missing out</u> . Perhaps it also shows that Sumayah longed to be like others, and could also indicate her perception of a difference between her and other children. I interpret that Sumayah perceives this time as a period in which <u>family</u> was of great importance to her. She details playing board games with her father and playing with her brother. She also recalled that she received numerous <u>gifts</u> following her procedure, suggesting the love and support given to Sumayah at this time. Sumayah also spoke about the intense <u>pain</u> associated with the procedure, when medical staff removed the drain.
	Sumayah was told by her consultant that her kidney would not last forever. Sumayah also experienced complications after her transplant when her kidney started to bleed	<ul style="list-style-type: none"> • “I didn’t really know that and it was quite difficult” • “Knowing that I won’t have any kidneys in me and I’d be limited ” • “I found out that I’m gunna have to be on dialysis again. When I’m older I’m gunna need another transplant, I’m 	Sumayah described two related turning points during her experience of hospitalisation. Experiencing complications with her kidney transplant and being told that her kidney would not last forever mark a difficult time for Sumayah. I interpret this as a period of <u>realisation</u> for Sumayah, in which she was forced to unexpectedly come to terms with the impermanence of her kidney, which she did not foresee. I interpret this to have been a <u>shock</u> for

“The Roller-Coaster of the Odd Life”²¹			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
	(*turning points*)	<p>gunna... need to be in hospital again and I didn’t really want that”</p> <ul style="list-style-type: none"> “I just got really upset knowing that I won’t have no kidneys.” 	Sumayah, especially as she was enjoying having a kidney. She had to <u>come to terms</u> with the reality of how things would be from then on (being on dialysis, needing another transplant, regular attendance at hospital etc.).
	At aged 10 years, Sumayah saw the HS for the first time	<ul style="list-style-type: none"> “I remember seeing it for the first time and I was like why hasn’t anyone ever told me about this” “It was bright, it was colourful, it was fun.” “I just loved it everything about it I love it like the teachers they were super friendly...I used to look forward to school.” “You’d meet other people from other wards and just interact with different people.” 	Sumayah describes the first time she experienced HS in positive terms, including its <u>physical environment</u> , the <u>atmosphere</u> (“fun”) and the <u>friendly nature of the teachers</u> . Sumayah looked forward to going to HS which further demonstrates Sumayah’s <u>enjoyment</u> of HS. Sumayah even stated that she preferred HS to her home school ²² . Sumayah highlighted the role of HS regarding <u>social interaction with other hospitalised CYPCCs</u> from other wards who she would not ordinarily interact with. I interpret that for Sumayah HS provides the opportunity for ‘ <u>normalcy</u> ’. Furthermore, HS <u>reduces anxiety</u> about missing out on educational opportunities.
	Sumayah met two playworkers for the first time	<ul style="list-style-type: none"> “She’s been here for <u>quite a while now</u>. I was admitted on her first day at work and we’ve got such a nice relationship” “It’s like everyone from the school and from the playworkers they’ve just got this relationship and <u>everyone knows everything</u> in a good way” 	Sumayah met the current playworkers during this time, with whom she has a good relationship. I interpret Sumayah’s positive evaluations of playworkers to be connected to their perceived <u>commitment, persistence and consistency</u> . Sumayah suggests that HS staff and playworkers build relationships which are based on <u>openness and communication</u> .
	In 2011, Sumayah had pneumonia	<ul style="list-style-type: none"> “Like you’re not allowed to <i>laugh</i>... I remember watching ‘You’ve Been 	Sumayah identified having pneumonia as her worst moment during her experience of hospital. She explained

²² In this study, I refer to ‘home school’ meaning the mainstream school at which CYPCCs are on roll, at the same time as they receive schooling in the hospital context.

“The Roller-Coaster of the Odd Life” ²¹			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
	(*worst moment*)	<p>Framed’ with my Dad and we was laughing and then your chest feels tight and you start huffing and puffing and it’s just not a nice time”</p> <ul style="list-style-type: none"> “I was in intensive care and they don’t have TV there – had to watch loads of films repeatedly” 	that she was <u>forbidden to drink</u> and also to do simple things, such as laughing. Sumayah also identified feeling <u>restricted physically</u> in terms of her wider environment, in a sense trapped. Sumayah also reported the <u>boredom</u> associated with this experience.
Chapter 3: 14 – 16 years (the present)	Sumayah received an Xbox and a quad bike from her family	<ul style="list-style-type: none"> “I spent all afternoon testing out all my new games. And had all the modern games... And just felt amazing.” 	Sumayah’s description of recently receiving an Xbox and a quad bike indicates <u>excitement</u> .
	Sumayah attended the secondary school department of the HS	<ul style="list-style-type: none"> “I’ve been doing my GCSEs and my teachers that come here have helped me out a lot” “It was Chinese New Year and they built a trolley dragon and it was really fun it was very more hands-on than actual work and they always know how to make the work and the lessons more fun” “Like they don’t pressure you to work hard... but they help you achieve your possibilities just by not pressuring really” 	Sumayah indicates the positive impact of HS teachers, in helping her to <u>prepare for her GCSE exams</u> . She identifies an individual teacher who has particularly helped her. I interpret that Sumayah is <u>grateful</u> for the academic support she has received at HS. Sumayah indicated that the physical environment differed between the secondary and primary departments of the HS. Sumayah described the HS’s approach to work as <u>fun</u> and <u>hands-on</u> , an approach to learning which Sumayah prefers. Sumayah also indicated that the HS <u>does not apply too much pressure</u> on students, which Sumayah indicates is advantageous.
	Sumayah went to London for the first time on a hospital trip	<ul style="list-style-type: none"> “One of them [HS teachers] always comes and I love it when [name of HS teacher] comes because she’s such a happy person and she like she makes the 	Sumayah visited London for the first time. She evaluated the visit not in terms of what she did or saw in London, but rather in terms of the people who were with her, namely HS teachers. I interpret this to reflect the <u>positive</u>

“The Roller-Coaster of the Odd Life” ²¹			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
		atmosphere very nice place”	<u>impact</u> some <u>teachers</u> have had on Sumayah.
	Sumayah started on home haemodialysis treatment	<ul style="list-style-type: none"> • “The best thing about it I get free weekends so... I get to stay in bed as long as I want” • “I can be more independent. It’s more suitable times, it’s nocturnal so it does it overnight instead and I can go into education full-time” 	I interpret that Sumayah has <u>quickly become accustomed</u> to her new treatment and is <u>knowledgeable</u> about its requirements. Sumayah emphasised the new <u>freedom</u> offered by home haemodialysis, e.g. not being required to go into hospital on weekends. Furthermore, Sumayah expressed that home haemodialysis permits her <u>greater independence</u> , e.g. regarding treatment times.
Future chapters	Sumayah would continue to be on home haemodialysis and have a second transplant	<ul style="list-style-type: none"> • “Be getting my second transplant, being the first in [name of city] to do home haemodialysis” 	Given the happiness and freedom Sumayah described when she previously had a kidney it is unsurprising that receiving another kidney transplant is important to Sumayah. She also expressed that she will be first in the city on home haemodialysis treatment, which appears important to Sumayah.
	Sumayah would go to college (to study Health and Social Care) next year and then go to university	<ul style="list-style-type: none"> • “College full time, And then going into uni” • “I’d do nursing or something to do with social working... helping” 	For Sumayah attendance at college on a <u>full-time basis</u> appears important. Sumayah would like to attend university which I interpret as representative of her <u>ambition</u> , also demonstrated by her desire to achieve success in her GCSE exams. Sumayah expressed her desire to enter a <u>helping profession</u> (nursing/social care). I interpret that this could be as a result of the positive impact hospital professionals have had on Sumayah’s hospital and HS experience.

4.2.4. Themes

Using a thematic approach, 8 themes were identified in relation to Sumayah's narrative, as represented in Table 24. Codes were initially identified based on Sumayah's original transcript and these codes were then grouped into themes (see Appendix 17 for exemplars of this process). Table 24 details the 8 themes with exemplary quotations which are used to support the identification of each theme.

Table 24: Thematic analysis - key themes interpreted from Sumayah's narrative

Themes	Exemplary quotations	Interpretation
1. Knowledge and understanding	<p>"Usually if I was on the normal haemodialysis I would only do 3 times a week at 4 hours. But with the new one it's very important to do 20 hours per week"</p> <p>"I've gone older I've known what's been going on... started putting the pieces together and needed to take more notice"</p> <p>"I can understand things now. But it's a positive and negative."</p> <p>"Sometimes you just wanna shut down and pretend you don't know what they're on about... no-one likes bad news."</p>	<p>A predominant theme in Sumayah's narrative is knowledge. Sumayah was clearly knowledgeable about technical aspects of medical intervention, such as the different requirements for different types of haemodialysis and the purpose of a drain. This acquisition of knowledge appears to be associated with Sumayah's age and as she became older, her understanding increased. Sumayah acknowledged that increased knowledge is positive, but it also has drawbacks because fully understanding when there is bad news can be upsetting.</p>
2. Independent living	<p>"But the best thing about it I get free weekends... I get to stay in bed as long as I want"</p> <p>"Because I could really just go out and be more active and have more of a social life"</p> <p>"But me being me I was too busy on focused on things that were either irrelevant or just not that much important."</p> <p>"It means having a life. Being able to eat what you want,</p>	<p>Sumayah referred to independence often, particularly relating to her new treatment, which offered increased flexibility and freedom concerning the treatment demands. Sumayah also referred to the freedom and independence a kidney transplant gave her, e.g. regarding eating, drinking and social life. Sumayah expressed that she was too preoccupied with other minor things to really appreciate the kidney as much as she should have done. This may be indicative of feelings of guilt, blame and</p>

Themes	Exemplary quotations	Interpretation
	drink what you want not be told to stop drinking. You can go out more frequently and your life didn't revolve around the hospital."	regret. Sumayah appeared to be involved in self-management of her condition and was aware of how to care for a kidney transplant. Sumayah identifies the struggles of trying to manage her treatment schedule and doing all the 'right' things for self-care, but the outcome of this not always being within her control.
3. Being different	<p>"Which is home haemodialysis and I am the first in [name of city] on it"</p> <p>"There's more than just one thing to deal with with me"</p> <p>"I'd have to say it's happiness but also I'd have to say different. Different to most... Most kids my age ...Sometimes different is good."</p>	Occasionally Sumayah indicated that her experience of hospital was different to other hospitalised CYPCCs. Furthermore, Sumayah also expressed that she has had a different life experience to most other CYPs more generally. This is reflected in her title 'The Rollercoaster of the Odd Life', in which she implies the difference of her life experience compared to the 'norm'. This difference can lead to feelings of 'missing out' for Sumayah e.g. thinking about others playing. Sumayah referred to "me being me" at times, again indicating her self-perception as unique and different.
4. Fun times and fun people	<p>"I was just living life"</p> <p>"It [HS] was bright, it was colourful, it was <i>fun</i>"</p> <p>"Like I used to go to the park... go to ride my bike with my brother. We used to even go running sometimes just for fun"</p> <p>"Just for fun, she said let's do a cooking lesson and we made chocolate chip cookies. She was an English teacher but all round fun person."</p> <p>"She's been a big help because she's always been happy... even on a day when I was down, she knew how to lift me up and she's always been good at that"</p>	Fun is predominant in Sumayah's narrative. She reminisced on fun times, particularly when she was younger and enjoyed life in a care-free way. She also spoke about HS and the fun activities there. Sumayah expressed that 'fun' and 'happy' people (e.g. HS teachers) were important to her hospital and HS experience and had a positive impact on her. Additionally, Sumayah referred to having fun with her family both in and out of hospital. I interpret fun to be important to Sumayah as it signifies her enjoyment of childhood, positive wellbeing and possibly is a means of distraction from illness and hospital-related matters.
5. Relationships	"She used to always talk to me and we played Scrabble when she was pregnant. She passed away. She was ill but she was one of the best playworkers	Sumayah's relationships recur frequently during her narrative. Sumayah expressed positive relationships with loved ones demonstrated by the time they spent with her and the presents given to her following

Themes	Exemplary quotations	Interpretation
	<p>ever”</p> <p>“I can pretty much tell her anything... And she knows how to always help me”</p> <p>“We’ve been really close we’ve been on trips together... We’ve even stayed up pretty much all the night in hospital”</p> <p>“She’s like more of a sister slash best friend and I will miss her”</p> <p>“I think it’s been about 4 to 5 years we’ve known each other”</p> <p>“She’s helped me through a lot. Like we’ve been close and been together really”</p> <p>“Very close to him he’s been my consultant from the start”</p>	<p>medical procedures and more generally. Sumayah detailed positive interactions with playworkers in the hospital and they appear vital in supporting her. Central to how Sumayah perceives her relationships with adults in the hospital, is the length of time they have been involved in her care. Sumayah also detailed her positive relationships with other hospitalised CYPCCs and the fact that she relished the opportunity at HS to meet other CYPCCs from different wards. Sumayah identified another hospitalised CYPCC as her best friend, from whom she received emotional support. Sumayah expressed that the two are very close and have known each for a long time.</p>
6. Passivity in care versus active partnership	<p>“They decided it was a change for me and they wanted to give me a change and they set me up to do next stage which is home haemodialysis”</p> <p>“I’m staying here... Yeah they’re gunna keep me for a bit longer than the other patients”</p> <p>“We’re working on that [home haemodialysis] now”</p> <p>“It’s more of <i>should</i> I have it like they asked me and I did want it”</p>	<p>Sumayah’s narrative presents a contrast between her role as a passive recipient of medical intervention, in which treatment is simply done <i>to</i> her, and Sumayah as an active partner in her care. Sumayah highlighted the influence of medical professionals in her care, which is understandable given their expertise. However, this could reflect Sumayah’s perceived vulnerability more generally by adults. Conversely, Sumayah also referred to her active participation in her care, e.g. being asked for her opinion. Sumayah’s use of the word ‘we’ refers to this partnership between adults (medical professionals and parents) and herself.</p>
7. Ups and downs	<p>“Had my kidney infections, chest infections had pneumonia but I got through that.”</p> <p>“Roller-coaster ... I had my ups and I’ve had my downs. But either way I’ve still enjoyed life”</p>	<p>A theme in Sumayah’s narrative is that of the shifting nature of her experience of hospital and HS. She describes her experience in metaphorical terms (a ‘roller-coaster’), although she still notes that her experience has been positive despite this.</p>
8. Pain/ discomfort/ sickness	<p>“They use like a sharp point thing and they took out the stitches and they <i>pulled</i> it and just the thought of it makes you feel sick”</p>	<p>Sumayah detailed several painful procedures. These incidents appeared to be vividly remembered and were unpleasant aspects of Sumayah’s hospital experience. The painful experiences had such an impact</p>

Themes	Exemplary quotations	Interpretation
	“I had it done quite recently when I got my kidney taken out again and <i>yes again</i> , and afterwards I just felt really hot and flustered and I just felt <i>sick</i> ”	on Sumayah that the thought of the procedure alone made her feel sick. Sumayah drew comparisons to when a drain was removed more recently and she felt the same unpleasantness, suggesting that experience does not help to make these procedures any easier.

4.3. Chapter summary

This chapter presents my interpretations from the narrative of one participant, used as an exemplar of the analytic process. The four phases of analysis conducted for each of the five participants allowed me to recognise that although participants shared the common experience of hospitalisation and HS, the individual stories of each CYPCC differed considerably. Not only did the individual events vary between participants, but also the meanings ascribed to these events. A summary of the key findings from all five participants are presented in Table 25.

Table 25: Summary of key findings in relation to participants’ experiences of hospital and hospital school

Participants	Key findings about participants’ experiences of hospital and HS
1. Suzan	<ol style="list-style-type: none"> 1. <u>Family presence</u> in hospital, particularly her parents and older brother. 2. <u>Growth, development, progress and change</u> – regarding her academic skills and independence 3. <u>HS</u> as a valuable resource, in supplementing her education outside of school as well as at one point being her only source of formal education. 4. <u>Impact of nurses</u> – they were seen as fun in addition to being kind and helpful and had a great impact on Suzan’s experience of hospital and future ambitions. 5. <u>Physical pain and restriction</u> – many procedures were described in terms of intense physical pain and the associated restrictions, for example regarding movement. 6. <u>Adult care</u> – Suzan was anxious about her imminent transfer to adult care. 7. <u>Boredom</u> in hospital regarding lack of activities and entertainment at times 8. <u>Other hospitalised CYPCCs</u> – Suzan developed relationships with other hospitalised CYPCCs of all ages.

2. Farah	<ol style="list-style-type: none"> 1. <u>'A big family'</u> – Strong relationships in hospital particularly other CYPCCs (friendships), playworkers and nurses. 2. <u>Routine/getting used to things</u> - becoming accustomed to the way of things was important for Farah and was interpreted as a way by which Farah felt stability and security. 3. Anticipation/sadness regarding <u>transition to adult care</u> 4. <u>Kidney transplant</u> – this was regarded as life-changing for example regarding energy, body image/physical appearance, fewer restrictions and more freedom. 5. <u>Adults in hospital</u> were seen as important, particularly playworkers, doctors and nurses. They provided her with emotional support, fun activities and administered the correct medicines to help Farah to get better. 6. <u>Pain</u>
3. Sumayah	<ol style="list-style-type: none"> 1. <u>'Having a life'</u> – quality of life, freedom, independence versus restriction and being limited 2. <u>Relationships</u> – CYPs (one best friend and other hospitalised CYPCCs) and adults (playworkers, HS teachers and doctors) 3. <u>'Ups and downs'</u> throughout her experience of hospital and HS 4. <u>Emphasis on care-free times</u> – periods of time, particularly when she was younger when she did not worry. This was sometimes associated with not understanding fully about the nature of what was happening. 5. <u>Fun people and fun</u> for example in reference to the HS regarding environment, teachers, activities and approach to teaching. 6. <u>Knowledge and understanding</u> about her condition, which has increased over time. This is regarded as both positive and negative for example when Sumayah realised that her kidney would not last forever which was difficult and disappointing for her 7. Feelings of <u>difference</u> and <u>missing out</u> when comparing her experiences with that of other CYPs (non-hospitalised CYPs without health issues). 8. <u>Active versus passive participation/involvement in own healthcare</u>
4. Rose	<ol style="list-style-type: none"> 1. <u>'Normal' self versus ill self (identity)</u> - a contrast throughout the narrative between Rose's 'normal' self and when she is ill 2. <u>Pain</u> regarding medical procedures and as part of the presenting symptoms relating to her health condition 3. <u>Boredom</u> in hospital associated with her lack of hospital schooling 4. <u>Special adults (nurses and HS teachers)</u> who go beyond their job roles 5. <u>Support and comfort</u> provided by her family (primarily mother and grandparents) and teddies 6. <u>Communication with adults</u> - sometimes adults attempted to communicate with her, however at other times Rose was not informed of certain things, which she did not like. 7. <u>Unpredictability about health and future health</u> despite Rose's attempts at self-management of her health
5. Sajid	<ol style="list-style-type: none"> 1. <u>Knowledge and understanding</u> in relation to his own condition and also other health conditions, which has developed over time

	<ol style="list-style-type: none"> 2. <u>Other people</u> – Sajid’s heightened awareness of what other people might think or say about him and the fact that others can never truly understand his experiences 3. <u>Going home</u> was particularly significant in Sajid’s experience which was indicative of his displeasure when in hospital, particularly for longer periods. 4. <u>Uncertainty</u> regarding the changing nature of his health, e.g. how small infections can quickly escalate, in addition to uncertainty about his treatment 5. <u>Positive thinking</u> was important for Sajid. He compared his own health with that of others with perceived worse conditions to put his own health into perspective. Sajid also thought positively when considering his future. 6. <u>Parents</u> were regarded as important in relation to support, access to medical care and helping with his healthcare.
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In the following chapter, the findings presented in Table 25 are discussed in relation to existing literature, followed by a discussion of implications of these findings in terms of professional practice.

5.0. DISCUSSION

5.1. Chapter overview

In this chapter I consider the key findings from the current study, as discussed in Chapter 4, with reference to relevant existing literature (reviewed in Chapter 2). Due to the richness of data, it was not possible to discuss every finding from each participant in detail in relation to existing research. I have therefore chosen to prioritise discussion of *key* findings from participants' narratives in order to privilege detailed in-depth discussion of significant findings over surface discussion of all findings. The rationale for consideration of 'key' findings was based on the following aims: i) elevation of the CYP's voice (e.g. if an idea was given particular attention and focus within individuals' narratives), ii) selection of dominant themes from the analytic process (i.e. if the idea arose in multiple participants' narratives) iii) focus on HS and CYPCCs' educational experiences in hospital²³ and iv) relevance to practice. Based on these criteria, the following areas are prioritised for discussion in relation to RQ1: family, personal growth, health-related identity, relationships, coping, unpredictability and uncertainty and medical intervention and physical pain. Importantly, in relation to RQ2, education in hospital is the final area discussed in this section, in line with the unique contribution that this research offers to existing literature. Finally, I consider the implications for professional practice.

²³ The area of CYPs' experiences of hospital schooling was identified in Chapter 2 as a gap in the literature, which the current study aimed to address. This area is a unique contribution of the current study, and was therefore prioritised regarding findings to be discussed in detail in this chapter.

5.2. Discussion of findings in relation to Research Question One: What are the meanings for CYPCCs of their experiences of hospitalisation?

5.2.1. Family

All participants indicated that family, especially parents, were significant to their hospital and HS experience. Literature too suggests that parents are an integral part of the hospital environment for hospitalised CYPCCs (Carney et al., 2003; Aldiss et al., 2009; Lambert et al., 2014b). All participants referred to the importance of having their parents physically present with them while in hospital. This is supported by literature, which suggests that parental separation is negatively associated with CYPs' emotional wellbeing (Bowlby and Robertson, 1952; Robertson, 1958; Rokach and Parvini, 2011) and is linked with fear (Coyne, 2006; Salmela et al., 2010). In the current study parental presence was associated with emotional support and comfort, particularly after medical procedures. Literature suggests that parental presence can facilitate CYPCCs' pain management and CYPCCs' coping in hospital (Pölkki et al., 1999; Forsner et al., 2005; Aldiss et al., 2009; Rokach and Parvini, 2011).

Findings from Suzan's narrative suggest that family circumstance is important in CYPCCs' experience of hospital. When Suzan's father was not in the UK, additional strain for her mother negatively affected Suzan's wellbeing. Conversely, Suzan's father's arrival to the UK was positive for her. This is supported by literature which shows that increased family connectedness and cohesion are associated with higher levels of CYPCCs' emotional wellbeing (Wolman et al., 1994; Szyndler et al., 2005; Piazza-Waggoner, et al., 2006). Wolman et al. (1994) even suggest that family connectedness is more significant to CYPCCs'

wellbeing, than the CC itself. Furthermore, Vessey (2003) identifies that parental equilibrium affects a child's psychosocial response to hospitalisation.

From her active involvement in the narrative process, it was clear that Sajid's mother had her own 'parent narrative' to convey (see Appendix 18 for quotations relating to her parent narrative), based on her experiences as a mother of a hospitalised CYP. This is reflected in existing literature, which depicts an intense emotional journey for parents of CYPCCs (Granek et al., 2014; Bunn, 2015). However, Sajid's mother's active involvement in the narrative generation process, may not only reflect her desire to surface her own narrative, but may also reflect an over-protectiveness and perceived vulnerability of her son. Although there was no evidence of this from the narrative produced, parental over-protectiveness is negatively associated with CYPCCs' wellbeing, for example decreased self-esteem and higher anxiety levels (Blum, 1992; Manuel et al., 2003). Furthermore, parental psychological distress and perceived child vulnerability are reported to significantly predict adolescent anxiety (Lopez et al., 2008).

In addition, Sumayah referred to the time spent with her family in hospital, for example watching television and playing board games, which was important to her. Sumayah also spoke of the gifts she received from loved ones following a significant medical procedure which I interpreted as indicative of the love, support and attention Sumayah received from family at this time. Literature indicates that CYPCCs enjoy the time spent with parents in hospital and the increased attention they receive (Jensen et al., 2012).

Although it is suggested that hospitalised CYPs miss their family, including siblings (Coyne, 2006; Aldiss et al., 2009; Rokach and Parvini, 2011), only two out of four participants with siblings, mentioned their siblings' presence in hospital as important and it is interesting that these were both older brothers. Another interesting finding of the present study, one often absent in existing literature, is the significance of grandparents. For Rose, her maternal grandparents played an important role in her hospital experience, visiting her in hospital and were *like* parents in their own right, according to Rose. Not only did they support Rose's mother, but in the likely absence of a father figure (and siblings), these family members were even more vital for Rose. Likewise, for Farah, who also never mentioned a father figure at any point, her grandmother also played an important supporting role in her hospital experience. The importance of a support network around the family (and CYPCC) is supported by Winnicott's notion of a 'nursing triad' in which a new mother is emotionally supported by another person, in order for the mother to effectively care for her baby (Winnicott, 1958). Similarly, the role of extended family in emotionally supporting parents of CYPCCs is vital as this containment allows the parents to attend fully to their ill child, without extraneous worries or stresses about the external world.

In addition to human family members, Rose also referred to her 'teddies' as sources of support and comfort, particularly due to their presence during medical scans. This is supported by Winnicott's theory of 'transitional objects', which indicates that objects may act as 'soothers' for CYPs in moments of stress or anxiety (Winnicott, 1971). Moreover, literature indicates that CYPCCs bring toys from home in order to personalise their hospital space and to bring 'home comforts' to the clinical environment (Boswell et al., 2000; Carney

et al., 2003; Lambert et al., 2014b). However, teddies' presence during medical procedures as a form of comfort is not represented in existing literature and thus appears to be a new contribution.

5.2.2. Personal growth

Participants highlighted the importance of growth, progression and development in their experiences of hospital and HS. Participants often referred to development in terms of knowledge and understanding, particularly regarding their CC and related treatment, which increased with age. Sumayah and Sajid were able to talk about rather technical aspects of their medical care, demonstrating their large knowledge-base. Increased knowledge was perceived positively and contributed to treatment compliance and decreased anxiety and/or fear associated with treatment. However, increased knowledge was also contrasted, in Sumayah's narrative, with being young, not understanding things and as a result this time was characterised as care-free and fun. This suggests that knowledge brings an added burden. Furthermore, increased understanding was also associated with the full realisation of bad news, which could be upsetting.

The finding that the development of knowledge and understanding is central to CYPCCs' experience of hospitalisation and attendance at HS is not reflected in the literature. This is surprising, given the predominance of this finding in the current study, particularly for participants with extensive experience of hospital and HS, spanning years. One possible reason for its lacking presence in literature could be due to the narrative nature of the

present study which lends itself to participants' reflection of a phenomenon over time. Looking back at personal experiences from the beginning of their hospital experience to the present and future, may be more likely to produce narratives which emphasise personal growth and development.

Another interesting finding in terms of development of knowledge and understanding was Sajid's active knowledge-seeking about other medical conditions. This facilitated acceptance of his condition as well as changing the perspective from which he viewed his own health, i.e. thinking that his condition, despite its severity, was not 'the worst'. This is largely ignored in literature regarding CYPCCs' coping. Notably, literature identifies that a coping method for CYPCCs is discovering a new baseline, which involves avoiding comparison to healthy peers and creating a different standard for their lives (Christian and D'Auria, 1997; Rhee et al., 2007). This reduces a sense of difference in CYPCCs' lives (Christian and D'Auria, 1997) and gives them a sense of control over their health (Rhee et al., 2007). However, currently literature fails to address coping in terms of comparison to other CYPCCs and 'worse' health conditions, which appeared to be an effective coping strategy for Sajid in the current research.

5.2.3. Health-related identity

All participants referred to their perceptions of how health-related factors impacted on their constructions of themselves and their lives ('health-related identity'). This suggests elements of CYPCCs coming to know and understand their CCs, the impact on daily life and

what this means for them. Participants discussed their health-related identity as key to their hospital experience, regarding lifestyle, perceived difference and contrasting identities.

5.2.3.1. Lifestyle

The findings suggest that CYPCCs often associated having a CC with constraints to daily life. Suzan, for example, referred to restrictions in terms of her school attendance, her movement and everyday tasks such as showering and eating as a result of her condition and medical treatment. Similarly, Farah indicated that she had constraints regarding her consumption of food and drink. It is argued that treatment burden exists for CYPCCs, which may inflict additional worries for them (McCaffrey, 2006; Hegarty et al., 2008). Moreover, loss of self-determination in terms of loss of independence and restriction to activities can induce fear for CYPCCs (Coyne, 2006) and can impact on CYPCCs' social relationships with peers (Spirito et al., 1991; D'Auria et al., 2000; Meijer et al., 2002).

5.2.3.2. Perceived difference

Findings by Christian and D'Auria (1997) and Rhee et al. (2007) suggest that CYPCCs can feel a sense of difference to their healthy, unaffected peers, which can be associated with emotional pain (Woodgate, 1998). The current study supports this assertion as CYPCCs expressed feelings of being 'different' to others, including other hospitalised CYPCCs, other CYPs and others generally. Sometimes participants longed to be like others, for example playing (Sumayah) and not coming to hospital (Rose), which is supported by literature.

James and Curtis (2012) indicate that although hospitals attempt to downplay the idea of the 'sick child' and thus difference, by emphasising 'normality', this is only effective for young children and not CYPs aged 11-16 years. Participants in the current study certainly perceived themselves as different due to their illnesses and their related lifestyles. Furthermore, James and Curtis (2012) argue that CYPs can feel disconnected from their everyday lives, a disconnection which becomes more profound as they approach adulthood and that fosters feelings of isolation and alienation characteristic of the 'sick adult'. This point is supported by the present study as Sajid expressed that other people may not (or cannot) truly understand his experience as a CYPCC, which not only suggests a sense of difference but also isolation and loneliness, which is typical for hospitalised CYPCCs (Wilson et al., 2010). Furthermore, Forsner et al. (2005) found that CYPCCs may experience feelings of being the only ones who can experience their illness-related life experience and others, even parents, could never truly understand. In addition, Sajid also expressed preoccupation with what 'other people' might think or say, even lying to protect how he might be perceived. This aligns with the interactionist model of illness (Llewellyn and Hogan, 2000), which follows that a person's sense of self (identity) and behaviour as 'ill' or 'disabled' is impacted by others' (and society's) view of them.

In the current study some CYPCCs felt a sense of 'missing out', in comparison to other CYPs. This is consistent with the suggestion that CYPCCs want to live their lives as 'normally' as possible and keep up with healthy peers (Rhee et al., 2007; Ferguson and Walker, 2014). Missing out is associated with feelings of loss, sadness, frustration and/or unfairness (Rhee et al., 2007; Wilson et al., 2007).

5.2.3.3. 'Normal self' and 'ill self'

Rose's narrative reveals a strong sense of her shifting identities between her 'normal self' and her 'ill self' and was the only participant to view her health-related identity in this way. I interpret this to be reflective of her good health until the age of 9 years, which is relatively long compared to other participants, who have been unwell since an earlier age. Therefore, Rose's perception of herself as 'normal' i.e. in good health may be more prominent in her narrative than for others. Her 'normal self' entails Rose's engagement in her regular routine and activities such as dancing, going to school, going on family holidays and visiting her grandparents, whereas her 'ill self' is described in terms of being "not right" and not being able to do these things. Literature indicates that disruption to normal routines and everyday activities can cause fear and anxiety for CYPCCs (Coyne, 2006; Rokach and Parvini, 2011). Furthermore, I interpret the identity change from her 'normal self' to her 'ill self' to be indicative of grief and loss for Rose, which confirms findings from Forsner et al.'s (2005) research. In this study, CYPCCs reported feelings of 'being lost' regarding physical changes and 'not being the same anymore', e.g. feeling weak, tired and being trapped in a 'sick body'. This suggests an element of the 'ill self' as almost unrecognisable to Rose's identity in relation to her 'normal self' in good health.

5.2.4. Relationships

Findings from the current research demonstrate that relationships in hospital were integral to the hospitalisation experiences of all participants. One participant referred to her relationships in hospital in terms of being like 'a big family'. Findings concerning CYPCCs'

relationships with key adults in hospital as well as other hospitalised peers are now discussed in relation to relevant literature.

5.2.4.1. Key adults

The current study suggests that CYPCCs perceived relationships with key adults as central to their hospital experiences. CYPCCs distinguished between different professional roles, namely consultants, playworkers and nurses, which contradicts the findings of Jensen et al. (2012). Furthermore, CYPCCs reported the nature of their relationships and the impact of these relationships on their experiences.

Findings demonstrate that positive relationships developed with nurses were central in all the CYPCCs' experience of hospital. Participants indicated that nurses were kind, fun and encouraging and were perceived to administer correct medications for the benefit of CYPCCs' health. Furthermore, findings from the current study indicate that CYPCCs learned from nurses, which appeared to influence two of the participants' future ambitions to enter helping professions. Findings also indicate that these relationships were lasting and were developed over perceived long periods. This is supported by literature which indicates that hospitalised CYPCCs can have positive relationships with nurses (Carney et al., 2003; Board, 2005). However, the findings in the current research go beyond previous findings to look at the specific nature and impact of the relationships between CYPCCs and nurses, for example influencing CYPs' career ambitions.

Furthermore, findings demonstrate that CYPCCs sometimes favoured some nurses - Rose even gave her preferred nurses affectionate nicknames. She preferred these nurses in particular, because she perceived them to 'understand' her, pay attention to her and were 'funny' and 'silly'. Rose contrasted this to other nurses who she perceived to simply do their jobs, and nothing more. Findings from Coyne and Kirwan (2012) indicate that CYPs perceived healthcare professionals both positively and negatively, for example describing them as intelligent, friendly, funny and providers of medicines but on the other hand not having much time for patients. This is reflective of Rose's experience with nurses (and HS teachers - see Section 5.3.2), in that she perceives a stark contrast between preferred nurses who she views as going above and beyond for her, and those she views negatively in simply performing their basic job duties.

Findings from the current study indicate that relationships with playworkers were significant for three participants. Relationships with playworkers were viewed positively and these practitioners were regarded as doing exciting activities with CYPCCs, facilitating transition to adult care as well as providing emotional support for CYPCCs, through talking and elevating CYPs' moods when they were feeling low. Literature supports the value of the hospital play specialist role for hospitalised CYPCCs, providing emotional support via play-based activities (Barnes, 1995; Shipton, 1999; Ellis, 2000; Nuttall, 2013). Yates et al. (2009) also suggest the importance of non-healthcare professional roles in hospital, for example youth workers, in supporting hospitalised CYPCCs and developing positive relationships with them. However, the current research also builds on existing findings as Sumayah's narrative indicates that

relationships with playworkers were viewed positively when the adults demonstrated commitment, persistence and consistency.

Relationships with consultants were also seen as important to the hospital experiences for four out of five participants. CYPCCs perceived consultants as authoritative figures who made important decisions about their healthcare. Despite difficulties, for example struggling with the amount of prescribed medication (Farah), participants generally viewed doctors positively based on their perceived good intentions, which is in line with literature (Board, 2005). This finding also contradicts existing literature suggesting that CYPs regard doctors both positively and negatively (Carney et al., 2003; Coyne and Kirwan, 2012).

It is possible that the relationships participants developed with hospital-based professionals, such as nurses, playworkers and HS teachers (see section 5.3.2) may encompass attachment components, and these adults may even be considered 'secondary attachment figures' for CYPCCs. Bowlby (1973, 1982) describes secondary (or 'subsidiary') attachment figures as special people in a CYP's life, with whom they have developed a close secondary attachment bond. Although these figures may be very influential only for limited periods in someone's life (Ainsworth, 2006), Bowlby (2007) indicates numerous benefits of this type of attachment relationship, regarding CYPs' resilience, mental health, social and cognitive development and for supporting families. Babies and toddlers will often develop secondary attachments to people their primary attachment figure (often the mother) knows well and whom they both see frequently, for example relatives and neighbours (Bowlby, 2007). For

older CYPs, non-parental adults may offer attachment-related safety and security, especially as adolescents seek independence from parental influence by exploring alternative sources of security and support (Van Ryzin, 2010).

5.2.4.2. Communication with adults

Findings from the current research suggest a difference between adults' active communication with CYPCCs about their own healthcare and when this does not occur. Findings from thematic analysis of Sumayah's narrative indicate that during her hospitalisation experience there was a mixture of her role as both passive recipient of medical intervention and active involvement in her own care, when she was asked for her opinion and consulted on healthcare matters. Furthermore, findings from the restorying process of Rose's narrative indicate that she was frustrated when not informed by adults of the insertion of a nose tube, which caused her significant pain and discomfort. Literature indicates that lack of information can induce fear for CYPCCs (Salmela et al., 2010) and providing information is a matter of rights (Bricher, 2000; Noyes, 2000). Nevertheless, although hospitalised CYPs should be and want to be involved as partners in consultation and decision-making regarding their health care, this is often not executed in practice (Bricher, 2000; Nebrig et al., 2004; Coyne, 2006; Coyne, 2008; Van Staa, 2011; Wechter, 2014). Literature suggests there are barriers to CYPs' involvement such as adults' perceptions of hospitalised CYPCCs (Bricher, 2000; Coyne, 2008) and deficiencies in meeting CYPs' communication needs (Coyne and Kirwan, 2012; Lambert et al., 2012).

5.2.4.3. Hospitalised peers

Literature suggests that CYPCCs can encounter difficulties with social interactions with their peers (Spirito et al., 1991; Pfeffer et al., 2003) and peer interaction can cause stress and concern for them (Seiffge-Krenke and Stemmler, 2003). Interestingly however, findings from the current study indicate that non-hospitalised healthy peers were not considered significant during CYPCCs' experience of hospitalisation, and only one participant briefly mentioned these peers when considering her future (Rose). In addition, contrary to literature (Spirito et al., 1991), Rose did not anticipate there would be difficulties in interactions with non-hospitalised peers.

Although peers outside of hospital were regarded as largely insignificant to CYPCCs' experience of hospitalisation, relationships with other hospitalised CYPCCs were perceived as vital. These relationships were considered at different levels: from viewing younger children with fondness, to interacting with peers at the HS, to forming friendships and even becoming best friends. Sumayah and Farah both identified having best friends (each other) who they had known for a long time and provided emotional support. Literature states that interaction with other hospitalised CYPs increases the likelihood of being understood and feeling equal for CYPCCs, which is important for their identity formation (Christian and D'Auria, 1997; D'Auria et al., 2000). Furthermore, peers are important for providing social support for CYPCCs during hospitalisation (Christian and D'Auria, 1997; D'Auria et al., 2000; Carney et al., 2003). The current research contributes a new finding to existing literature also: not only were other hospitalised peers a source of social support for CYPCCs, but also their families.

5.2.5. Coping

The present research indicates that hospitalised CYPCCs adopt an array of coping tactics, a finding supported by Boyd and Hunsberger (1998). This contradicts the assertion that the coping skills of this group of CYPs are limited and ineffective (Board, 2005; Rokach and Parvini, 2011). Findings associated with hospitalised CYPCCs' coping are now discussed.²⁴

Firstly, participants adopted positive thinking to facilitate their coping in hospital. Existing research supports the central role of optimism, maintaining a positive outlook on life and focusing on the positive outcomes of the CC in addressing daily challenges associated with CYPCCs' illness (Boyd and Hunsberger, 1998; D'Auria et al., 2000; De Ridder et al., 2008; Ferguson and Walker, 2014). Furthermore, Lynch et al. (2007) and Forsner et al. (2005) assert that adolescents adopt the cognitive strategy of positive self-talk, which is supported by findings from Sajid's narrative. Sajid focused on telling himself positive thoughts about his upcoming bone marrow transplant which he anticipated would give him a "new life". Sajid actively thought positively about the present as well as the future, in celebrating his accomplishments such as being able to ride a bike. Christian and D'Auria (1997) propose that an effective coping strategy for CYPCCs is to adjust their baseline by not comparing themselves to healthy peers. By celebrating achievements such as being able to ride a bike, which may seem insignificant to other 13 year olds, I interpret that Sajid has realised a new baseline for himself, which is not relative to his healthy peers.

²⁴ Findings regarding CYPCCs' coping pertaining to the role of social support from parents, other hospitalised peers and hospital staff are not discussed in this section as they are explored in other sections (Section 5.2.1, 5.2.4.1, 5.2.4.3 and 5.3.2).

Findings from the current study indicate that distraction was also a form of coping for hospitalised CYPCCs, particularly to avoid boredom. Thematic analysis suggests that participants actively attempted to keep themselves entertained during hospitalisation, for example playing games and music on their phones. Existing research supports this finding, indicating that CYPCCs use behavioural distraction techniques in order to shift their attention from hospital-related matters (Boyd and Hunsberger, 1998; Board, 2005; McCaffrey, 2006; Lynch et al., 2007). Furthermore, Pölkki et al. (2003) indicate that CYPs want to be distracted, specifically relating to pain management. However, the current study also contradicts Lynch et al.'s (2007) finding regarding sex-based preferences regarding coping strategies. Lynch et al. found that boys tended to prefer behavioural distraction, which was not the case in the present study, with three girls in particular who reported the use or desired use of this coping strategy.

Ferguson and Walker (2014) suggest that having clear goals for the future is an effective coping strategy for CYPCCs, as aspirations can increase motivation to overcome short-term challenges and positively impacts on CYPCCs' sense of empowerment and control in their lives. The restorying aspect of data analysis in the current research indicates that several participants were ambitious and had specific aspirations for their future, such as achieving well in their GCSE examinations, going to college and becoming healthcare professionals.

In addition to findings which support previous research, the current study also makes new contributions to existing literature. Firstly, the present study indicates that self-

management and attempts to manage some aspects of their CC may be a coping strategy for some hospitalised CYPCCs. Rose, for example, spoke about maintaining a 'clean diet' with prescribed regulations. Despite not fully comprehending the reasons behind the specifications, Rose showed a commitment to adhering to medical advice. I perceive this to be indicative of her attempt to impose some control over a somewhat helpless situation. Furthermore, an interesting finding largely ignored in literature, is CYPCCs' use of knowledge and understanding in relation to their CC, their treatment and even others' conditions, to cope with everyday challenges. Future research is recommended to further explore if and how knowledge and understanding plays a role in CYPCCs' coping experiences and its level of effectiveness.

5.2.6. Unpredictability and uncertainty

Hospitalised CYPs experience a range of emotions, including uncertainty (Salmela et al., 2010), which is affirmed by the current research, particularly in relation to CYPCCs' health and treatment. Rose, for example, unexpectedly and devastatingly relapsed after she appeared to have recovered. Likewise, Sumayah emphasised the unpredictable nature of her health by likening her experience to a 'roller-coaster'. Furthermore, Sajid indicated that his health is particularly unpredictable because smaller infections can quickly escalate to become more serious. Crossland (2002) found that the greatest source of academic anxiety for CYPCCs stemmed from their inability to control the impact of their medical condition on their physical and academic capabilities.

5.2.6.1. Transition to adult care

The current research indicates that CYPCCs were apprehensive about the uncertainty associated with transitioning to adult care. Despite visiting the adult hospital, Suzan and Farah conveyed fear and anxiety about transferring to a new environment which was perceived to be considerably larger and where the staff and routines were unfamiliar. Furthermore, participants expressed that they would miss nurses and hospitalised peers. This is in line with Tuchman et al.'s (2008) research which indicates that prior to transfer to adult care CYPCCs only expressed negative opinions about transition. Like the present study, CYPCCs expressed concern about ending close established relationships and entering into an unknown way of actualising medical care (Tuchman et al., 2008). Literature indicates that transition to adult care can be challenging for CYPCCs (Fleming et al., 2002) and needs to be well-supported and co-ordinated (Jalkut and Allen, 2009).

5.2.6.2. CYPCCs' perceived futures

The current research indicates that participants were uncertain of their future health and future medical interventions. Some CYPCCs hoped they would receive vital transplants (kidney and bone marrow) and hoped that these life-changing procedures would be successful to ensure positive life changes for them. Concerns about their future health were in part due to what they had learned about the unpredictability of their health status. Rose's narrative suggests that she had learned of the constant possibility for unexpected change regarding her health, as a result of the sudden onset of her relapse, after having appeared to have fully recovered from ill-health. This finding supports existing literature which

suggests that CYPCCs experience additional worries as a result of their conditions, such as worries about their future health, the possibility of experiencing relapses and developing health complications (Cappelli et al., 1989; Woodgate, 1998; McCaffrey, 2006). Many participants in the present research prioritised being in good health for the future and did not wish to attend hospital frequently and undergo medical treatment.

The restorying aspect of analysis in the present study indicates that many participants were ambitious in terms of their future, which is a suggested coping strategy for CYPCCs (Ferguson and Walker, 2014). Aspirations included achieving well in examinations, attendance at college full-time, going to university, entering nursing or social care professions and living abroad. Participants' demonstration of ambition and aspirations appears to contradict Woodgate's (1998) finding that CYPCCs worry about future career choices and whether their illnesses could limit their opportunities. However, elements of doubt in Farah's narrative about becoming a hairdresser in the future, despite already undertaking the necessary qualifications, could be indicative of worry about the impact of her health on future career prospects.

5.2.7. Medical intervention and physical pain

Findings from the current research indicate that physical pain was integral to CYPCCs' experiences of hospitalisation, which is supported by existing research. Twycross and Collis (2013) indicate that 58% of children in their study experienced severe pain and 24% moderate pain. Furthermore, Sermet-Gaudelus et al. (2009) report that although pain is

more intense and longer for adults, there is no significant difference between the rate and recurrence of pain between CYPs and adults.

Participants spoke about intense pain and sickness predominantly in relation to medical procedures and their presenting symptoms upon first admission to hospital. Although CYPCCs indicated that the pain was addressed by pain relief measures, the detail in which participants described their pain and the predominance of this theme amongst different narratives suggests the significant impact of pain on their hospital experiences. For Sumayah, the thought alone of a particular painful procedure made her feel 'sick', also indicating that undergoing painful procedures does not become easier over time. The finding that CYPCCs are negatively impacted by physical pain is supported by existing literature which ascertains the association between physical pain and emotional wellbeing for CYPCCs. The possibility of painful medical procedures may cause anxiety (Rokach and Parvini, 2011) and fear for CYPCCs (Forsner et al., 2005; Coyne, 2006; Salmela et al., 2010), which may in turn increase physiological feelings of pain (Pölkki et al., 1999). However the current study contradicts findings from Jensen et al. (2012) which found that although CYPs had negative thoughts about the possibility of pain, they reported that the medical procedure was actually harmless. In contrast, CYPCCs in the present study recalled painful medical procedures in vivid detail and with emphasis in their expression. This contradiction in findings may be because Jensen et al. (2012) focused specifically on blood samples being taken, whilst in the current study CYPCCs mentioned a variety of medical procedures, which may have been more significant and less transient than drawing blood.

For CYPCCs in the present study, pain and sickness were not only associated with difficult feelings for themselves and their families, but also with restriction and boredom. For participants, extreme pain was often connected to restriction in terms of movement and daily tasks (showering, eating and drinking). Although existing research indicates that CYPCCs worry about practical difficulties as a result of their condition (Rhee et al., 2007; Wilson et al., 2007) the current study suggests that CYPCCs are also concerned about the practical difficulties and restriction induced by painful experiences.

The present research indicates that medical intervention was not only associated with pain, but also with the impact of treatment burden on CYPCCs' desire to go home. Sajid's treatment demands were regarded as excessive and at times unmanageable, meaning treatment was particularly stressful and unpleasant for him. This led to Sajid's desire to go home as quickly as possible. Literature indicates that CYPs' quality of life is lower in hospital than at home and lower as an inpatient than as an outpatient (Hegarty et al., 2008; Speyer et al., 2009). This has negative implications for hospitalised CYPs' wellbeing and supports the finding about Sajid's strong desire to go home. Furthermore, research indicates that the ultimate relief for hospitalised CYPs is going home (Carney et al., 2003; Wechter, 2014).

5.3. Discussion of findings in relation to Research Question Two: What are the meanings for CYPCCs of their experiences of hospital school?

5.3.1. Hospital school as a valuable resource

Findings from the current study suggest that HS was generally regarded as a valuable resource. Suzan and Sumayah in particular emphasised the important role of HS during their hospital experiences, highlighting the valuable academic support provided to prepare them for their GCSE examinations, for which they were extremely grateful. This type of academic support is particularly vital as school attendance is often an issue for CYPCCs throughout their illness (Abrams et al., 2007) which decreases opportunities for academic success (D'Auria et al., 2000). Furthermore, literature indicates that this type of academic support is particularly vital as academic achievement is significantly associated with self-concept for CYPCCs (Yan et al., 1999). The academic support provided by HS was particularly vital for Suzan as she indicated that it supplemented her learning at her home school and at one point was her only means of formal education due to severe ill-health. The finding that HS provides CYPCCs with academic support follows statutory guidance (DfE, 2013a) which emphasises that continuity of CYPCCs' education is of the utmost importance.

Additionally, Sumayah reflected that HS reduces anxieties about missing out on educational opportunities as a result of hospitalisation, which she now recognises as important much more than when she was younger. This is consistent with existing research which suggests that hospitalised CYPCCs worry about school (Wolman et al., 1994). In addition, consistent

with literature (Wiles, 1987), Sumayah reported that HS provided an opportunity for normalcy (“a place where you can just be at school”).

However, HS was not a dominant feature of some narratives (Farah and Sajid), possibly indicating the lack of impact of HS on their overall hospital experience. This suggests that for some children, HS can play a valuable role, but for others this is not the case. This variation is an interesting and valuable finding, which builds on existing research.

5.3.2. Hospital school teachers

For some participants, HS teachers were prominent in their narratives and evidently played a significant role in their experience of hospital and HS. Suzan and Sumayah spoke about individual teachers’ positive attributes such as: their fun-loving nature, friendliness, encouragement, happiness, thoughtfulness and kindness, which the CYPs reflected on positively. Suzan and Sumayah also noted their appreciation for teachers’ efforts in supporting them and inferred that they interpreted their efforts as surpassing their teacher role. Literature indicates the vital role of HS teachers in keeping CYPs occupied during their hospitalisation and preserving a sense of normalcy for them by maintaining a hospital-school connection (Wiles, 1987). Furthermore, HS teachers provide academic support (Lian and Chan, 2003) and also social and emotional support for hospitalised CYPs (Watanabe, 2013). As discussed previously in Section 5.2.4.1, non-parental adults such as teachers may act as secondary attachment figures to CYPs, providing support and emotional security to students when required (Thijs and Verkuyten, 2012; Ramsdal et al., 2015). Moreover,

Crossland's (2002) research identified that the rapport between HS teachers and students was a motivating factor for CYPCCs' academic endeavours.

However, the findings from the current research also contradict existing research concerning the important role of HS teachers. Some participants' narratives scarcely featured HS teachers and thus, for some participants, teachers do not appear to have made much of an impression. Rose for example, explained that she only knew two HS teachers, who she liked and favoured, and the way Rose perceived HS teachers varied considerably depending on their presence and how she attributed the causes of their absence.

In both Farah and Sajid's narratives, HS teachers were barely mentioned in contrast to other professionals who appeared to have played a larger role in their experiences, such as playworkers, consultants and nurses, who were spoken about with fervour. Sajid appeared not to have met many HS teachers, although the ones he had met were regarded as 'nice'. In Farah's narrative, HS teachers were not mentioned. This finding on the variability of the presence and impact of HS teachers on the evaluations of CYPCCs' experiences of HS is a new finding which contributes to existing research.

5.3.3. Hospital school environment

The current study indicates that the physical appearance of the HS environment was noticed and viewed positively, for instance the 'bright' and 'colourful' physical environment, noted

by Sumayah. Literature suggests that CYPs prefer a colourful physical environment (Boswell et al., 2000; Koller and McLaren, 2014; Lambert et al., 2014). Furthermore, adolescents can evaluate the hospital's physical environment on a profound and analytic level, in terms of how it makes them feel emotionally (Ullán et al., 2012; Koller and McLaren, 2014). Therefore, Sumayah's evaluation of the HS's physical design may reflect how the school's 'fun' and friendly atmosphere made her feel.

The present study demonstrates that CYPCCs perceived a social aspect to HS. Participants stated that the HS afforded opportunities for social interaction with other hospitalised peers, particularly ones who they may not have otherwise encountered due to their location on different wards. Literature suggests the importance of these interactions for CYPCCs, particularly as hospitalisation can contribute to feelings of disconnectedness with peers at school, which can lead to social isolation and a reduction in opportunities to feel socially competent (Blum, 1992; D'Auria et al., 2000). Furthermore, literature highlights the value of interaction between CYPCCs and peers with CCs as they may share similar illness-related life experiences and thus have feelings of being understood by these peers (Christian and D'Auria, 1997; D'Auria et al., 2000). Finally, literature indicates that hospitalised CYPCCs want to feel connected to the internal hospital community (Lambert et al., 2014a) and be with children of a similar age (Boswell et al., 2000), both of which HS can provide.

In the current research CYPCCs' valued the approach to teaching and learning adopted in the HS. Sumayah identified that the approach to work was fun and "more hands-on than

actual work”, which she preferred. The fun nature of HS was associated with Sumayah’s enjoyment of the school and she even stated that she preferred it to her home school. Likewise, Rose spoke about HS lessons in terms of being enjoyable and practical, which she indicated was a motivator for her engagement, even when she was not at optimal health. This is supported by Crossland (2002) who found that when the topic was appealing, CYPCCs felt most academically efficacious.

Additionally, Rose indicated uncertainty about her HS lessons, for example having some lessons and not others. Moreover, in a previous hospital Rose reported that she did not receive much schooling because the teacher did not know she was there. The flexibility in HS arrangements is supported by literature which indicates that teaching in this context involves flexible prioritisation, primarily with scheduling and learning goals (Burns, 2013). DfE statutory guidelines (2013a) also state that CYPs with medical conditions should have access to a suitable, flexible and responsive education appropriate to their needs.

Findings from the current research highlight CYPCCs’ perceptions of the expectations placed on them as students. Rose and her mother spoke about ‘gentle pushing’ employed by HS teachers which they found beneficial for Rose. By contrast, Sumayah spoke of the minimal pressure placed on her as a student, which she liked. This interesting finding about hospitalised CYPCCs’ experience of HS highlights a need for further investigation into the expectations and/or level of pressure placed on hospitalised students.

5.4. Implications for practice

Based on the findings from the current research, I propose numerous implications for professional practice, primarily in terms of supporting CYPCCs in education, which directly relates to RQ2. I focus on education because this makes the most novel contributions to research and is also most relevant to my perspective as a TEP. In this section, I suggest recommendations for both EP and HS practice. Of note, some recommendations may not only be relevant for EPs and HS staff, but also for CYPCCs' home schools and other medical and educational professionals.

5.4.1. EP practice

Findings from the current research, which explored hospitalised CYPCCs' experiences of hospitalisation and HS, and their interpretations of these experiences, highlight some practical implications for EPs. To structure this section about the implications for EP practice, I have utilised Bronfenbrenner's (2005) bioecological model which is a systemic model used to explain the development and behaviour of people. This model (Figure 2) indicates that interactions between the individual and their wider environment (known as 'proximal processes') are the key mechanisms which produce human development and behaviour (Bronfenbrenner, 2005). It is proposed that the developing person, the environmental context (both close and distant) and time periods in which these interactions take place significantly influence the quality of the proximal processes and subsequently human development and behaviour (Bronfenbrenner, 2005; Bronfenbrenner and Morris,

2006). Bronfenbrenner (2005) suggests numerous interrelated systems which can influence these interactions (Figure 2). I apply this framework to my EP practice, in adopting approaches which consider CYPCCs within a context of wider systems, for example using psychological frameworks in assessment such as the Interactive Factors Framework (Frederickson and Cline, 2002) or Miller and Leyden's (1999) theoretical framework in which the individual is at the core of numerous psychosocial systems. Furthermore, I consider the necessity for EPs to take a holistic and person-centred approach in needs formulation. I have chosen to adopt this approach in my research, applying Bronfenbrenner's (2005) bio-ecological framework to the implications for practice for EPs, based on my findings from the current research.

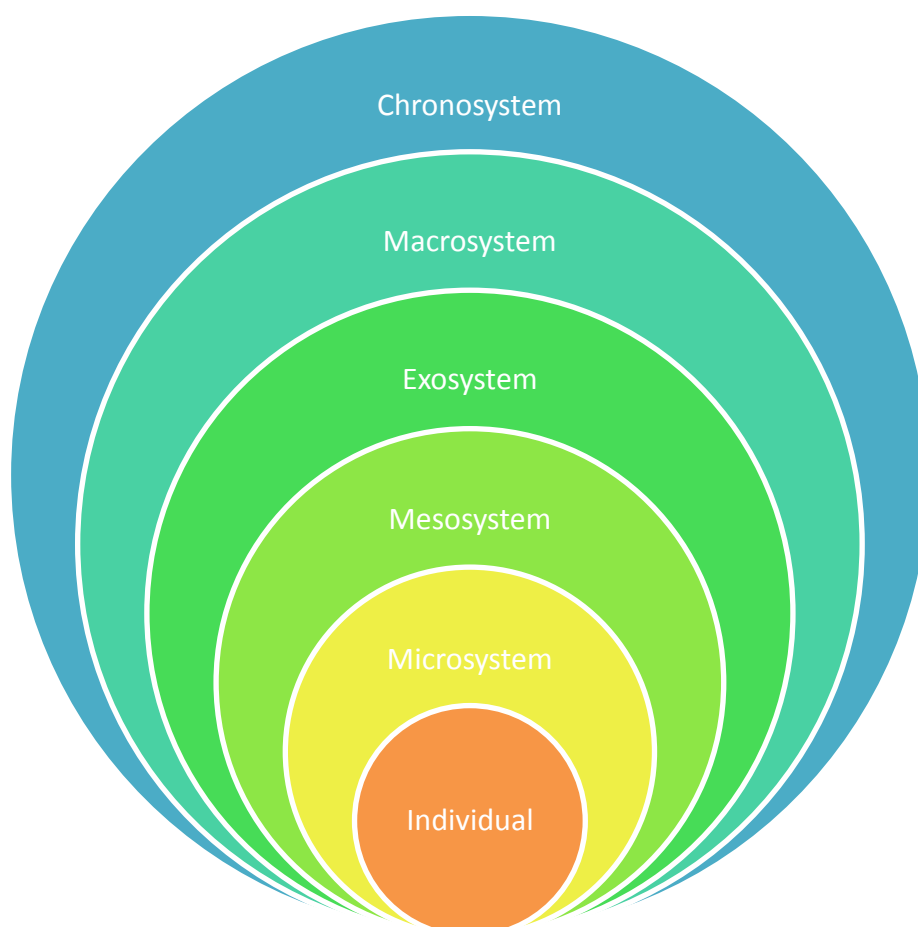


Figure 2: Bronfenbrenner's (2005) bioecological model of context systems

As Figure 2 demonstrates, the bioecological model places the CYP at the centre, which is known as the 'individual' context system. At this level, the bio-psychological characteristics of the person are the focus. It is argued that individual disposition can activate proximal processes in a particular developmental area and sustain their functioning (Bronfenbrenner and Morris, 2006). At the individual level, bio-ecological resources of ability, experience, knowledge and skill are necessary for the effective functioning of proximal processes at all developmental stages (Bronfenbrenner and Morris, 2006). Furthermore, demand characteristics of the individual are crucial to encourage or discourage responses from the social environment which can nurture or disturb the functioning of proximal processes (Bronfenbrenner and Morris, 2006). In the context of my research, the individual context system refers to the individual CYPCC with experience of hospitalisation and HS.

The next context system is called the 'microsystem'. Bronfenbrenner (1994, p. 39) indicates that a microsystem is "a pattern of activities, social roles and interpersonal relations experienced by the developing person in a given face to face setting... that invite, permit or inhibit engagement in sustained, progressively more complex interaction with, and activity in, the immediate environment e.g. settings including family, school". In the context of my research the microsystem encompasses the CYPCC's immediate family (including parents), hospital (including medical professionals), HS (including HS teachers) and the CYP's home school.

The 'mesosystem' is the context system outside of the microsystem. This system "comprises the linkages and processes taking place between two or more settings

containing the developing person... the mesosystem is a system of microsystems”

(Bronfenbrenner, 1994, p. 40). For my research, the mesosystem may involve relations between home and HS/home school, between HS and home school or between home and hospital, for example. The fourth system in Bronfenbrenner’s bioecological model is called the ‘exosystem’ which “comprises the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person”

(Bronfenbrenner, 1994, p. 40). In this system, the events which occur indirectly influence processes within the immediate setting in which the individual is situated (Bronfenbrenner, 1994). For my research, this is less relevant as the research does not involve settings which do not have direct interactions with the CYPCC. However, the exosystem in this context may involve a parent’s workplace and home/HS/home school/hospital.

The next system in Bronfenbrenner’s (2005) framework is called the ‘macrosystem’. This refers to the attitudes and ideologies of the overarching culture, including “the belief systems, bodies of knowledge, resources, customs, life-styles, opportunity structures, hazards and life course options” which are entrenched in the micro, meso and exosystems (Bronfenbrenner, 1994, p.40). In the context of my research, the macrosystem may involve legislation, policy and research influencing the overarching knowledge and beliefs concerning hospitalised CYPCCs. The final system proposed by Bronfenbrenner (2005) is the ‘chronosystem’ and refers to the environmental changes (or consistencies) that occur over time (Bronfenbrenner, 1994). My research requires CYPCCs to recollect and reflect on past experiences and the meaning of these experiences and therefore, the element of time is apparent, as is inherent in narrative research. The chronosystem in the context of my

research therefore may refer to environmental changes over the life course, such as family structure or hospitalisation patterns as a result of changes in health over time.

In this section I discuss implications for EP practice, using Bronfenbrenner's (2005) bioecological model as an overarching framework, to explicitly link the implications for practice to three 'levels' at which EPs may work (individual, microsystem and mesosystem).

5.4.1.1. Individual level

Regarding EPs' work at an 'individual' level (Bronfenbrenner, 2005) EPs should consider the resources CYPCCs possess. Firstly, for most CYPCCs a school's EP could have a positive impact in offering supplementary support to strengthen and build upon CYPCCs' existing coping strategies. Findings from the current research indicate that CYPCCs adopt certain coping strategies for coping generally with their experience of having a CC as well as strategies specifically relating to the hospital context. Secondly, EPs should be aware of and anticipate CYPCCs' use of alternative coping strategies and should encourage the development of already established effective coping strategies for CYPCCs. Findings from the current study point to participants' use of alternative coping strategies, not necessarily mentioned in existing literature. Sajid, for example, used his knowledge of other medical conditions to conclude that his health was not the 'worst', which helped him to cope.

5.4.1.2. Microsystem level

Regarding Bronfenbrenner's 'microsystem' level, there are several implications for EP practice, in terms of working directly with CYPCCs. The unique nature of each narrative in the current research indicates the need for EPs to take a person-centred approach when working with CYPCCs, treating each CYPCC as an individual and not making assumptions (about a CYP's experiences and/or the CYP's interpretation of these experiences) without supporting evidence from the CYP themselves. Person-centred approaches are firmly grounded in psychology and are based on Rogers' (1959) person-centred theory, which assumes the inherent tendency of humans toward growth and development and highlights the importance of self-determination (Patterson and Joseph, 2007). Sanderson (2000) posits that person-centred approaches are not simply a matter of different assessment techniques, but rather a change to how CYPs with additional needs are perceived, and thus how their needs are conceptualised and understood by others in their microsystem (for example parents and school staff). Person-centred approaches are also promoted by the Children and Families Act (2014) and the associated Special Educational Needs and Disability (SEND) Code of Practice (DfE and DoH, 2014). Commitment to person-centred thinking should be in the fullest sense, for example considering CYPCCs' aspirations. EPs and other professionals should resist the urge to dismiss CYPCCs' personal ambitions in favour of what is perceived as 'realistic' or 'achievable' for the CYP, from their perspectives. I propose that it is the EP's role to continue to emphasise the raising of aspirations for this vulnerable group. Moreover, EPs have a valuable role to play in supporting and facilitating person-centred interactions between the CYP (individual) and other people in their immediate environment (microsystem).

The current research indicates that family factors (such as cohesion and parental presence) impact CYPs' experience of hospital, which is one example of an interaction between the individual and their microsystem. Another microsystem interaction is between the individual CYP and the EP. EPs could use narrative approaches therapeutically with CYPCCs to promote coherence in personal narratives, which could be advantageous for CYPCCs in order to engage in reflection, help them to make sense of their experiences, re-establish a sense of identity and recapture feelings of control. It is imperative that the timing of this work is carefully considered and it is critical that this work is not put into practice until the CYPCC is ready and willing. Professional judgement should be used. This recommendation relates to findings from the current study which indicate that narrative approaches give CYPCCs the opportunity to voice their story, which in turn helps them to make sense of their experiences and integrate these experiences into their identity. This can be a positive experience for CYPCCs, as it was for participants in the current study. Moreover, it may be advantageous for EPs to conduct (or recommend) individual/group work relating to identity and self-esteem for CYPCCs. This relates to findings in the current study indicating that some CYPCCs perceived a great difference between themselves and others, particularly their healthy peers, and sometimes worried about what other people thought about them.

5.4.1.3. Mesosystem level

For implications for practice at the mesosystem level, EPs can support CYPCCs by engaging in effective multi-agency work, collaborating with those professionals who work directly with CYPCCs. Firstly, through skills in applying psychology and using formulation (HCPC,

2015) EPs can support others' understanding of complex situations such as the impact of CCs on CYPs and their educational experiences. In using consultation skills, EPs can facilitate joint problem-solving and can cultivate other professionals' skills to improve the support provided for CYPCCs.

In addition, It is important for EPs to link with staff in home schools and ensure that schools, in adhering to statutory guidelines (DfE, 2015; Public Health England (PHE), 2015) have a 'champion' who will promote emotional health and wellbeing across the school. It is possible that EPs could support schools' 'champions' to promote the emotional wellbeing for all students in the school, including CYPCCs. This relates to the findings from the current study which highlight that CYPCCs may be at additional risk regarding their emotional wellbeing.

One further implication for EPs' work at the mesosystem level is that EPs need to be aware and open to the possibility that parents of CYPCCs may also require support. EPs should be prepared to engage in family-based work to support the wider family, in particular parents, if required. With regard to the current research, the strong presence of Sajid's mother in her son's narrative and her desire to express her own narrative indicates that she evidently had her own story to tell of her experience as a mother of a CYPCC.

EPs may also work alongside other professionals (e.g. HS staff and home school staff) and parents at the mesosystem level, in recommending and encouraging preventative, universal

approaches which seek to improve resilience via the development of cognitive-behavioural techniques (e.g. FRIENDS programme, Barrett, 2005) in order to help CYPCCs to cope with a range of emotions they experience. These approaches could also be applied at the microsystem level, with EPs directly working with CYPCCs. Such approaches actively develop resilience, which may be beneficial for CYPCCs. CYPCCs may benefit not only from the psycho-educational components of such programmes (e.g. understanding how to recognise the physiological presentation of emotions), but also from the skill improvement aspect (e.g. learning to recognise negative automatic thoughts and convert them into positive thinking, relaxation techniques and mood monitoring). Cognitive-behavioural work is likely to support CYPCCs to continue coping over prolonged periods of uncertainty and negative emotions, associated with having a CC. It is important for CYPCCs to be equipped with a range of effective coping skills which they can choose to apply when necessary. This implication for EP practice is particularly critical given that the findings from the current research indicate that CYPCCs adopted both cognitive (e.g. positive self-talk, optimistic outlook, a focus on upcoming positive events) and behavioural (e.g. distraction) coping strategies.

5.4.1.4. Further recommendations

Overall, there are many implications from the findings of the current study in respect to EPs working at different levels and in multi-agency contexts. In terms of working to support CYPCCs at any level of Bronfenbrenner's system, I suggest that EPs need to recognise and understand CYPCCs' status as a 'vulnerable group' due to their needs and/or circumstances

which may make them prone to disadvantage compared to their peers. Due to complex life experiences and medical needs, CYPCCs may be at greater risk of emotional and social difficulties (see Literature Review). Despite CYPCCs' recognition as potentially vulnerable by Ofsted criteria and legislation through the Equality Act (2010), this acknowledgement and understanding is important for EPs. It is also important for this (albeit diverse) group of CYPs not to be *overlooked* by EPs or seen as potentially any less vulnerable than other groups, such as Looked After Children or CYPs from low income families. EPs' commitment to social justice (MacKay, 2010) requires that the profession be committed to supporting the inclusion of marginalised groups, including CYPCCs. EPs therefore need to ensure that CYPCCs are on their 'radar' by directly asking about the wellbeing of CYPCCs in schools.

Additionally, EPs may need to ensure that support is available for CYPCCs not only while in hospital or shortly following their return to the home school, but more generally over a longer period. EPs need to ensure that the support provided is suitable and at an appropriate time. This is in connection with the finding that all participants revealed that they regularly attend hospital several times and go back and forth between HS and their home school. Furthermore, literature indicates that there may be difficulties with CYPCCs' reintegration back to their home school and inclusion when they are there (See Section 2.6.3). EPs should be aware that at certain points CYPCCs may require more or less support. Findings from the current research indicate that at particular points, CYPCCs may experience different emotions, for example fear, anxiety and negative feelings in anticipation of transition to adult healthcare, at which stage they may require additional support. Conversely, there are also times when CYPCCs may be feeling more positive, for example

treatment changes or a kidney transplant may mean increased independence, freedom and a higher quality of life for a CYPCC. The CYPCC may therefore require less support and/or a monitoring phase in this instance.

In light of the current study's findings, I argue that EPs should act as advocates for CYPCCs and should be integral in affording them a voice, which is associated with control and choice. This is necessary in light of CYPCCs' experiences of CCs, which are often characterised by restriction, helplessness, lack of control and uncertainty about their treatment and health. Giving CYPCCs more control and choice is likely to elevate CYPCCs' self-efficacy and resilience and evade negative emotions regarding their lives and their identities. Finally, as supported by professional guidelines (BPS, 2009), and my own experience of data collection and analysis, I emphasise the necessity of EPs recognising the emotional impact of working with CYPCCs, and the important role of supervision as a platform for emotional processing.

5.4.2. Hospital school practice

The narratives from the current study highlight important implications in relation to HS practice, which are outlined in Table 26 below. Implications relate to HS teachers' practice, teaching and learning and approaches to teaching. Good practice already evident in the HS, as reported by participants in the study, is also highlighted. This section relates to EPs working at the 'mesosystem' level in Bronfenbrenner's (2005) model (see Figure 2), as it involves EPs supporting HS staff in their direct work with hospitalised CYPCCs.

Table 26: Recommendations for hospital school practice in relation to supporting CYPCCs

Area of practice	Recommendation	Related finding and/or justification
HS teachers	The consistency of HS teachers needs to be improved in practice in order for them to develop strong and meaningful relationships with CYPCCs.	Several participants referred to positive relationships with HS teachers which positively impacted on CYPCCs' experiences of hospitalisation and HS. These relationships also contributed to CYPCCs' emotional wellbeing, for example HS teachers were described as fun, happy, encouraging, thoughtful and kind and elevated CYPCCs' mood. Furthermore, Crossland (2002) found that CYPs' rapport with HS teachers contributed to their academic motivation. However, findings show that some participants did not know many HS teachers and the same teachers did not consistently teach them. Consistency of HS teachers is also in line with good practice guidelines (DfE, 2013a) which indicate that CYPs who cannot attend school due to health needs should have access to a broad and balanced curriculum.
	HS teachers should engage in open and honest communication with hospitalised CYPs, for example telling the CYP when they are or are not coming to teach them.	Rose's narrative indicated that she valued the communication of one HS teacher who informed her of when she would and would not be teaching her and when she needed to rearrange a lesson. Literature indicates the necessity of flexible scheduling when teaching CYPCCs. However, Rose indicated that it is necessary for the CYP to remain fully informed.
	HS teachers should attempt to introduce themselves to hospitalised CYPCCs, even if they do not anticipate seeing them often.	The current study indicates that some CYPCCs had met few teachers, for example Sajid and Rose, despite the CYPs being hospitalised for some time. Furthermore, Sumayah indicated that she would have liked to have been informed about HS earlier. I suggest that a consistent and co-ordinated approach should be taken by HS teachers to avoid potentially conflicting messages to hospitalised CYPs about the nature of HS and the role of HS teachers.
Teaching and learning	HS should continue to adopt 'fun' and 'hands on' learning activities for engaging CYPCCs in education.	Findings from the current study indicate that participants enjoyed practical activities, such as baking, and recalled them fondly. Furthermore, the current research indicates that such activities helped motivate students to engage in learning, even when they were not at optimal health.
	HSs should continue the	In the current study, CYPCCs referred to the

Area of practice	Recommendation	Related finding and/or justification
	good practice of providing high levels of academic support for CYPCCs in relation to GCSE examination preparation	academic support provided by the HS regarding examination preparation, for which they were extremely grateful. It could be that CYPCCs worried about missing school and worried about the likelihood of achieving well in their examinations and were therefore particularly appreciative of this support provided by HS teachers.
	HSs should endeavour to reflect the likely teaching and learning approaches of CYPCCs' home schools' learning environments, for example having different teachers for different subjects which is reflective of a typical secondary school learning environment. I understand this to be the case in the HS in which the research took place.	Findings from Sajid's narrative indicate that he valued that the HS had different teachers for different subjects, as this mirrored the established set up in his secondary school and was therefore familiar to him. Sajid indicated that in a previous HS, they had two teachers for all subjects which he found 'strange'.
Approach to teaching	For educational professionals working with CYPCCs, it is important to recognise that these CYPs may require additional encouragement to engage in learning and it is important not to concede without attempting to engage them first.	The research findings indicate that although CYPCCs may be unwell generally, at times when they are not they often prefer to be occupied, even if they do not appear this way. Encouragement and 'gentle pushing' were identified as beneficial for CYPCCs' engagement in learning tasks and to occupy them whilst in hospital which is advantageous for coping, wellbeing and preparation for returning to school.
	Educational professionals should be mindful of not applying too much pressure on CYPCCs. Professional judgement should be applied.	Sumayah's narrative indicated that she benefited from not having excessive pressure placed on her, which she perceived as helpful particularly in relation to achieving optimally in her GCSE examinations.
	Educational professionals should encourage and develop opportunities for social interaction	Findings indicate that CYPCCs valued meeting other CYPs at HS, for example from different wards, who they ordinarily would not have encountered. Literature also highlights that interaction with other

Area of practice	Recommendation	Related finding and/or justification
	between CYPCCs, for example through group work.	CYPCCs is very important, for example feeling equal and being understood in terms of similar illness-related experiences (see Literature Review).
	It may be beneficial for the HS to provide activities for CYPCCs by their bedside at times when hospital staff members (e.g. teachers, playworkers) are unavailable in order to keep CYPCCs occupied.	Findings from the current study suggest that CYPCCs experienced significant boredom while at hospital. Literature suggests that distraction is advantageous for shifting attention from hospital-related matters and also for dealing with pain (see Literature Review).
	Clear goals and aims for CYPCCs' futures should be encouraged.	Findings indicate that CYPCCs had aspirations for the future, for example attending college, university and becoming a nurse. Ferguson and Walker (2014) suggest that having clear goals and aims for the future is an effective coping strategy for CYPCCs to increase motivation to overcome short term challenges.

I propose that a more joined-up approach involving inter-agency collaboration, i.e. with CYPCCs' home schools may provide CYPCCs with continuity and consistency. Although guidance (DfE, 2013a) appears to suggest that collaborative working is preferred in the interests of CYPs with health needs, research literature also indicates the barriers to successful hospital-school liaison (see Literature Review). Additionally, whole school training may be appropriate for HS (and home school) professionals, with the aim of promoting the EP role, developing an awareness of potential issues associated with CYPCCs and building schools' capacity to support CYPCCs.

Lastly, I suggest that much can be learned from existing legislative guidance on supporting students with medical needs in education, such as DfE (2013a) and DfE (2014), and these

should be adhered to. However, I propose that it may also be beneficial to establish good practice guidelines, specifically relating to HSs, which take into account the unique setting and context of HSs and also the views of CYPs themselves, which the current research demonstrates are particularly valuable.

6.0. CONCLUSIONS

6.1. Overview

This concluding chapter considers how the findings from the current research have addressed the original aims of exploring CYPCCs' experiences of hospital and HS, and how this research is placed in the wider context of existing literature. First, I discuss the contributions of the current research to knowledge and theory and I make recommendations for future research. Next, I evaluate the efforts to heighten the research quality and reflect on limitations of the research as a result of the methodological choices made. Finally, I conclude the chapter with personal reflections and learning from the research process.

6.2. Contributions of the current research to knowledge

6.2.1. Hospitalised CYPCCs

Initially, I pointed out a gap in existing literature concerning hospitalised CYPs' narratives of their experiences of hospitalisation. Questions were also posed concerning the lack of literature about CYPs' experiences of HS, from their perspective, which appears vital particularly as many CYPCCs go in and out of hospital frequently and thus receive a large proportion of their education from HSs. The current research builds on existing knowledge about CYPs' experience of hospital, for example concerning health-related identity, key relationships in hospital with adults and other hospitalised peers, the importance of family, and the significance of medical intervention and physical pain in CYPCCs' hospital

experiences. Furthermore, the current research contributes original findings regarding CYPCCs' personal development during their time in hospital and CYPCCs' coping strategies, for example learning about other medical conditions, which facilitates the acceptance of their own health status. Furthermore, findings also indicate that CYPCCs' ambitions and goals for the future may contribute to their short-term coping.

The present study also spearheads knowledge in the field of HS in terms of practice and the experience of CYPCCs, which paves the way for further research in this area. Findings indicate that for some CYPCCs, HS (including HS teachers) is integral to their hospital experience, particularly in relation to the academic and emotional support they receive from staff, as well as opportunities to interact with other hospitalised CYPCCs. However, this was not the case for all participants and it was evident that for some CYPCCs, HS and HS teachers were not perceived as important to their hospitalisation experience.

6.2.2. Contributions to the field of narrative methodology

The present research contributes to theory in terms of developing understanding about narrative methodology. I conclude that narrative research with CYPs has been valuable in generating CYPs' event and experience narratives, which provided important insights into their interpretations of key events during hospitalisation and HS. I conclude that the adaptations made to suit the CYPs were necessary and effective in facilitating their access to the narrative interview, as discussed in Table 27.

Table 27: Reflections on how the adaptations made to the narrative interviews effectively facilitated CYPs' access to the narrative process

Adaptations and considerations made to suit the needs of CYPs	Reflections on how the adaptations facilitated CYPs' access to the narrative interview
1. Storyboard used in interviews	The storyboard used in the interviews was a beneficial framework and useful for all the interviews. Not only was the storyboard familiar to the participants, as anticipated, but it also helped CYPs to conceptualise their life in terms of a 'story' with discrete 'chapters' and was a visual reminder of the story concept throughout the interview.
2. Additional resources, including a variety of different coloured shapes	The additional resources, including a variety of different coloured shapes allowed for CYPs' creativity of expression, which I argue is advantageous. Researchers should be open to this and embrace creativity, resisting the temptation to view it as 'wasted time', but instead affording the opportunity for CYPs to become excited about and immersed in their narratives, which is likely to produce more detailed and fuller narratives. Sajid, for example had the idea of using a heart shape ripped into two to symbolise his worst moment which represented being 'heartbroken'. This conveyed the significance of Sajid's worst moment and gave me additional clues about the meaning the event had for him, which may not have been evident without the creative use of additional resources.
3. Conceptualising the narrative as a book with chapters	I conclude that conceptualising the narrative as a story, in terms of being a book with chapters was effective as it was understood by all participants and was familiar to them. However, I urge narrative researchers to be flexible in how the idea is conceptualised. In this study, not all CYPs liked books and so this could be off-putting for them, even before the interview had properly commenced. It is important for researchers to be flexible about conceptualising the 'story' idea, for example as a film or comic book, which was beneficial for some participants in this study.
4. Wording of narrative interview questions	I reflect that all interview questions appeared to be understood by CYPs, which was positive, except one referring to the idea of a 'turning point'. Only two participants fully grasped this notion and I therefore recommend that researchers consider how this idea might be explained in a more child-friendly and/or visual way. Alternatively, this question may be eliminated from the interview guide altogether.

I conclude that CYPs appeared to enjoy the narrative interview evidenced by high levels of engagement. Rose's mother attributed Rose's commitment to her desire to be "constructive" in the sense of doing her utmost to help others or 'give back' resulting from

her illness. I considered this an interesting response from Rose, and wondered whether other CYPCCs may have similar responses to ill-health, and may therefore demonstrate similar levels of engagement in the narrative interview process. Furthermore, I considered whether high levels of engagement in the interview were associated with boredom in hospital.

In addition, most participants responded positively to the question of how they were feeling at the end of the interview. Farah was the only participant who was “a bit upset”, although this was not due to the interview process itself but from the fact that it was her last day at the children’s hospital and she had had several interactions with others during the interview saying goodbye, including a particularly emotional one with her friend’s mother. Nevertheless, Suzan noted that she felt “nice” after the interview as it allowed her to reflect on past experiences of hospital and HS, which also helped her to see her personal progression since her first arrival at hospital. Sumayah too found the narrative interview an enjoyable and beneficial experience, as it offered her the opportunity to talk to someone about her life experiences. Moreover, Sumayah noted that she felt “comfortable” in the interview because it was “more informal than formal”, which is a point of consideration for researchers wishing to engage CYPs in narrative research.

Finally, I conclude that the present research has highlighted the potential value of parental presence during narrative interviews with CYPs. Although Sajid’s mother at times detracted from Sajid’s narrative, expressing her own experience as a parent, she also contributed

positively to Sajid's production of his narrative. Sajid's mother for example may have remembered something which Sajid did not, which then prompted him to expand on his mother's contribution. I urge fellow narrative researchers to consider this when interviewing CYPs. However, I also encourage researchers using narrative methodology with CYPs to exercise caution to ensure balance regarding parental contribution to safeguard CYPs' own words. It is more beneficial if parents do not talk over CYPs during the interview and/or suppress their narrative, which could be facilitated by the researcher setting out expectations or 'ground rules' at the start of the interview, emphasising the *supporting* role of parents and/or giving parents the opportunity to have their stories 'heard' beforehand.

6.3. Suggestions for further research

From this research I have identified several interesting avenues for future research: these are outlined in Table 28.

Table 28: Summary of recommendations for future research

Suggestion for further enquiry	Explanation
1. Further exploration into the role of family in CYPCCs' hospital experiences	Future research could explore the role of teddies and extended family, particularly grandparents, in supporting hospitalised CYPCCs, particularly when CYPs do not have support from both parents, as appeared to be the case for Rose and Farah. I also suggest that the role of siblings could be further investigated with regard to CYPCCs' experiences of hospital, particularly as they were scarcely referred to in the current research, and when they were, older brothers appeared to play the most important role.
2. Research into expectations and/or pressures of education for hospitalised CYPCCs and the impact of this on CYPCCs	Findings were mixed in relation to the perceived expectations and/or pressures placed on hospitalised CYPCCs regarding their education. This was an interesting finding and revealed an area which could be developed by further enquiry.
3. CYPCCs' future ambitions	The current study builds on Ferguson and Walker's (2014) finding that having aims and goals are a form of coping for

Suggestion for further enquiry	Explanation
	CYPCCs, however there is limited existing research about this. Further research could also explore how CYPCCs perceive their future and if/how their health impacts on their future ambitions. Comparisons could be made with healthy peers depending on the philosophical stance of the researcher.
4. Exploration of how CYPCCs' narratives change and develop over time and their associated meaning-making	Personal narratives can change over time, through childhood, to adolescence and then into adulthood, partly as a result of increased maturity and verbal competency, in addition to new meanings or insights gained from life experience (Gergen, 2004). A retrospective research design with adults who experienced paediatric CCs who may/may not continue to experience health difficulties may further illuminate how CYPCCs experience illness, hospitalisation and HS, the meanings they make of these experiences and how these experiences have impacted on their future.
5. The views of parents of CYPCCs	Although this was beyond the remit of the current research, it was evident from Sajid's interview that parents do have their own associated but <i>separate</i> story ('parent narrative') to convey. Sajid and his mother were almost competing at times to tell their stories (Sajid: "Mummy can I talk now?") and I therefore suggest it would be beneficial to explore the narratives of parents of CYPCCs. Furthermore, research could also explore the interaction between parents' narratives and how the CYPCC makes meaning of their experiences.

6.4. Evaluating the quality of research

I consider measures taken to heighten the research quality to be strengths of this research. As discussed in Section 3.7, I conceptualised 'validity' and 'reliability' in terms of 'trustworthiness' and 'dependability' respectively, in line with my social constructionist perspective. Trustworthiness refers to the accuracy of findings (Creswell, 2013) and whether conclusions drawn are well-grounded and supportable (Polkinghorne, 1988). Dependability, on the other hand, refers to the accuracy and accessibility of data (Webster and Mertova, 2007) and thorough auditing of the research process (Creswell, 2013).

The consistent use of evidence to support analysis throughout the study considerably enhances the quality of the research. This includes the use of numerous direct quotations from participants, which acts to persuade the reader of my interpretations of the findings (Reissman, 2008). Moreover, primary data in the form of transcripts (including one analysed transcript) are made available (Appendices 13 and 15) for readers to judge the conclusions made for themselves. Trustworthiness of the study was further strengthened by meticulous endeavours to ensure transparency throughout the research process, for example via the recording of data collection and analysis procedures (Reissman, 2008), which are detailed in Chapter 3. Furthermore, in being reflexive, I have acknowledged my own influences on my interpretation of findings, which addresses the possibility of plurality of meanings (Elliott, 2005) and allows the reader to judge the trustworthiness of claims in light of these influences.

Lastly, I consider that the impact of the current research is a noteworthy strength, which Yardley (2000) argues is a good criterion for assessing the value of research. My research leads to dialogue in terms of both future research and practice (implications discussed in Sections 6.3 and 5.4 respectively), which demonstrates its importance, particularly in light of gaps in existing research, highlighted in Chapter 2. Furthermore, I place the findings of the current research within the wider context of existing literature (Chapter 5) which demonstrates 'sensitivity to context' (Yardley, 2000) and further demonstrates the unique contribution of this research.

6.5. Reflections on methodological choices

6.5.1. Sample

In the current study, the sample can be critiqued in terms of two potential limitations: its generalisability and representativeness. Firstly, the small sample size ($n=5$) can be criticised for a lack of 'generalisability', an assertion grounded in positivism. However, I argue that the aim of this research was not generalisability, but rather an in-depth understanding of CYPCCs' experiences of hospital and HS and the significance of these experiences from the CYPCCs' perspectives. However, Elliott (2005) considers research pointless if deemed completely ungeneralisable. To this end, I adopted a 'common sense' approach to generalisability (Elliott, 2005) in which the reader decides for themselves whether the study's findings are transferrable and whether they can offer information about the same topic (CYPCCs) and in similar settings (e.g. other HSs). To enable readers to make these judgements, I provided rich contextual information about the participants and settings (Sections 3.8 and 3.9), although again, generalisability was not an aim of the study. I strived for in-depth detailed descriptions and contextualised data, rather than a large sample or generalisability; the 'trade-off' between depth and breadth (Elliott, 2005).

Furthermore, the research can be critiqued regarding the sample's limited representativeness of the population of hospitalised CYPCCs. Firstly, the small sample size and gender imbalance (4 females, 1 male) may lead some to argue that the sample cannot be representative of the population of hospitalised CYPCCs. Furthermore, at least one participant, Suzan, had English as an additional language and four out of five participants were from cultures outside of the majority population culture in the UK. Therefore, cultural

and linguistic influences may not only have impacted on how the narratives were constructed and these CYPs' narrative styles, but it could be argued that the sample is not typical of the wider population of CYPCCs. I argue however that I did not seek to achieve a 'representative' sample, and therefore did not randomly select participants. Instead, participants were selected based on the selection criteria (Table 14). Rather than seeking to ensure participants were representative of the wider population, I regarded each participant as unique and an *example* of the phenomenon being study.

6.5.2. Ethical challenges, interview context and participant recruitment

It is imperative to reflect on the ethical challenges encountered during the research, which in reality significantly hindered data collection. Firstly, securing ethical approval took much longer than anticipated, not only due to unfamiliar procedures and protocols, but also due to unforeseen obstacles²⁵, which led to considerable time delays in my research timetable, a difficulty not unique to my research (Stalker et al., 2004). Whilst the need for appropriate confidentiality, consent and protection is acknowledged, Stalker et al. (2004) point to the balance needed to prevent unnecessary impediments to potentially valuable and worthwhile research.

During data collection, ethical challenges arose regarding privacy and confidentiality. In the hospital there were difficulties obtaining a suitable room to guarantee privacy for the conversations and most interviews were carried out on the wards, by CYPs' bedsides

²⁵ Securing an honorary NHS contract (Appendix 20) and meeting with a consultant oncologist (assigned Clinical Lead person for the research), were but a few of the unforeseen elements which delayed the research.

(Section 3.9 describes interview contexts). Although curtains were sometimes pulled and some wards were quieter and more private than others, interviews were often subject to being within earshot of parents, healthcare staff and other children. This appears to be an issue inherent to the hospital context, as Coyne et al. (2009) describe similar difficulties.

The nature of the research context and stringent ethical requirements limited options for recruiting participants. The ethical procedures entailed the complex issue of dealing with multiple gatekeepers, whose 'stake' in the research was low. Although I vigilantly set the required ethical procedures in motion, Stalker et al. (2004) argue that action required to ensure smooth progress of the research is largely beyond the researcher's control. This was particularly evident in the HS context, in which two staff members acted as gatekeepers and upon whom I was heavily reliant due to ethical protocols. However, they were evidently busy and recruiting participants for my research was unlikely to be their priority. This was difficult for me as the researcher, because relying on the (limited) capacity and commitment of others meant that I was unsure whether the gatekeepers fully grasped the ethos, values-base and spirit of my research.

Furthermore, I became increasingly aware that the requirement for me to access CYPs via HS staff heavily influenced the availability of CYPs for the research. Coyne et al. (2009) highlight the problem with this as some individuals may be excluded from the opportunity to participate in research. This may be paternalistic and a type of over-protectiveness that leads to silencing CYPs and a denial of their rights (Miller, 2000; Coyne et al., 2009).

Furthermore, gatekeepers may have chosen to include some CYPs over others based on several factors including gatekeepers' assumptions about this research and research more generally, which CYPs would speak more favourably about HS staff, their assumptions about the health of CYPCCs and so on. This may have biased the research sample.

6.5.3. Interview design

Elements of the interview design can be critiqued, as detailed in Table 29.

Table 29: Summary of possible limitations to the interview design and justifications for these in the current research

Critique	Justification
The interview guide <u>avoided asking CYPs' about their lives</u> prior to their experience of hospitalisation. CYPs could mention their past if they deemed it relevant to their narrative, which some did.	The interview guide had an episodic rather than life-history nature as CYPCCs' lives prior to hospitalisation was not the focus of this research, but rather the episode of hospitalisation. It was also considered potentially burdensome for participants to recall their life history from birth, which may have been difficult for many reasons, for example memory abilities, temporal understanding, understanding of self and others and parental memory talk (Nelson and Fivush, 2004; Cleveland et al., 2005; Reese and Newcombe, 2007; Valentino et al., 2014). Furthermore, for some participants who were hospitalised from an early age, the vast majority of their life stories were incorporated into the episode of hospitalisation, and thus included in their narratives anyway.
The <u>alterations to the interview schedule</u> could be considered to compromise the fidelity of the narrative approach.	I agree with Murray's (2008) assertion that the aim of narrative interviews is to provide the best opportunity for participants to give detailed narrative accounts, which I prioritised over rigidly adhering to a pre-existing schedule, which in its original form, I judged unfit for the research purposes and unsuited to the participants in this study.
I acknowledge that during interviews, CYPs may have <u>reported what they anticipated would please me</u> .	Gergen (2004) proposes that individuals can purposely alter their narratives when they sense an unwanted response from the listener. Furthermore, CYPs may have wanted to preserve a more 'socially acceptable' narrative and/or identity, by for example portraying their successful management of the

	impact of their hospitalisation and illness, rather than emphasising their struggles. With this in mind, I emphasised to interviewees that this was <i>their</i> story, and that there were no 'right' or 'wrong' answers.
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6.6. Concluding comments

At the outset, this study aimed to explore hospitalised CYPCCs' narratives relating to their experiences of hospital and HS and the meanings they attributed to these experiences. This paper highlights the value of narrative research with CYPs and raises some important ethical challenges when seeking to access CYPs in the hospital setting. Furthermore, this study offers valuable findings which contribute to existing research concerning CYPCCs and hospitalised CYPCCs, including key relationships in hospital with hospitalised peers and adults, CYPCCs' health-related identity, the importance of family and the significance of medical intervention and physical pain in CYPCCs' hospital experiences. This study raised important practical implications for educational professionals working with CYPs with health needs, including the use of person-centred methods and specific intervention approaches to promote CYPCCs' wellbeing. Additionally, I argue that CYPCCs should be recognised and understood as a 'vulnerable group', and should be given a voice which is heard, in order to improve outcomes for this group of CYPs, in line with EPs' professional duty to social justice. Finally, the current study enriches an embryonic research topic regarding CYPs' experience of HS, and paves the way for further investigation into this area, with recommendations for future research including: exploration of the expectations and/or pressures placed on CYPCCs in terms of education, CYPCCs' future ambitions and how CYPCCs' narratives develop over time.

6.7. Personal reflections and learning

As a piece of narrative research, I feel it befitting to engage in personal reflection as I come to the end of the thesis as a way to be transparent about my personal journey as a researcher. The journey for myself from the outset of the research until now upon completion, has been momentous on both personal and professional levels. I will discuss my reflections and learning in terms of four areas as follows: the research process, the research topic, personal impact and impact on my practice as an EP.

Carrying out this research has meant that I have learned much about the process of research. Firstly, when I read the interview transcripts and listened to the audio recordings I recognised the development of co-construction of narratives in an interview context. I became increasingly aware of my own influence on participants' responses, for example by the leads I chose to pursue, my follow up questions and my responses to participants, which in itself was directly influenced by own understanding of the world as a result of my personal experiences. Furthermore, I learned not only about my influence on the co-construction process, but also about the participants' impact as a result of their comments and how these influenced my responses.

This research has allowed me to reflect on the nature of knowledge and the ways in which we learn about the world. I learned first-hand about the challenges facing social science researchers, particularly regarding the role of the educational researcher in clinical/medical contexts. I learned about the necessity of adapting to the research environment, which in

this case was the hospital context. This required patience and flexibility in order to negotiate the difficulties inherent in conducting research in the hospital, including NHS ethical procedures.

As a result of my full immersion in the research topic as a vital part of conducting this research, I now have an improved understanding of the experiences CYPCCs may have of hospitalisation, including HS. Furthermore, I have learned about the unique learning context of HS, which is unlike any other educational setting I have visited in my practice as a TEP. Working with this group of CYPs, I considered a real privilege in terms of being able to enter their space and hear their stories. This is certainly an insight I would never been able to access or co-construct without having conducted this research.

This research has also had a profound personal impact on me. The research journey has been a rich learning experience for me in terms of learning about myself and my values, for example the high priority with which I regard empowerment, social justice and facilitating the voices of the under-represented to be heard in research. I have also learned further about my personal qualities, particularly resilience, in overcoming numerous challenges and obstacles throughout the research process. I also now recognise my avid commitment to being a researcher-practitioner.

It is also important to recognise that the research has impacted me emotionally. At times I felt emotionally drained, particularly following interviews and during the analytic process.

During the interviews I felt as if I were occasionally 'containing' the emotions of participants, which was understandable given the reflective space which the interview provided for participants to contemplate past experiences and emotions related to these. Furthermore, listening to participants' stories was emotional for me as a result of my own personal experiences. Inevitably, there were some parts of participants' stories which caused me to feel sadness and helplessness, but unexpectedly I was also struck by narratives involving bravery and optimism, which were inspiring to me on a personal level. The emotional impact of the research was difficult to manage and required additional strategies for ethical reasons, in order to protect myself as a researcher, such as the maintenance of a reflective log and peer supervision. I have also reflected that despite the emotional impact of the research on me personally, in part due to my own life experiences and background, this was perhaps a positive factor in the co-constructions of narratives. Due to my high levels of empathy as a result of my own personal experience, I was highly tuned in to what participants were saying and demonstrated considerable sensitivity as a result. This influenced my ability to build rapport with participants and may have positively impacted on the CYPCCs' narratives regarding the richness of data produced.

With regard to my professional practice, this research will undoubtedly inform the ongoing development of my future practice as an EP. Firstly, this research has demonstrated that EPs have a key role in supporting CYPCCs, who I have argued are a vulnerable group. This research is likely to influence my practice when working with CYPCCs, as I will promote their need to access a high quality education and achieve academic success and be involved in all aspects of school life. I will endeavour to act as an advocate for this group of CYPs in the

contexts in which I work. The research reminds EPs of the difficulties some CYPs face in life and the potential impact of this on their education and opportunities. As discussed in Chapter 1, it is the professional duty of EPs to support CYPs at risk of disadvantage and their families, in line with a commitment to promoting equality of access for all CYPs.

The unique nature of each of the narratives is likely to ensure that I recognise the individual nature of CYPCCs' experiences of illness, hospitalisation and HS and not to make preformed evaluations about CYPCCs' experiences or their responses to these. Moreover, in light of the uniqueness of narratives more generally, I am aware that my assessments and/or conclusions are only one possible interpretation of a situation and it is critical to respectfully consider alternative narratives.

As a result of conducting this research, I have reflected that it is necessary to attend to the dynamic nature of all encounters, for example in professional meetings, recognising the subtle influences of myself on others and vice versa, in every interaction. From this research journey I have also learned about the importance of utilising research and psychology to influence EP practice, which ultimately promotes improved outcomes for CYPs. It is important for EPs to be ambitious in treading into new research territories, for example working in non-traditional spheres or with groups which are not traditionally 'mainstream' for EPs.

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APPENDICES TO VOLUME ONE

**IN HOSPITAL BUT NOT FORGOTTEN: AN EXPLORATION INTO CHILDREN AND YOUNG PEOPLE'S
NARRATIVES ABOUT THEIR EXPERIENCES OF HOSPITALISATION AND HOSPITAL SCHOOL**

By

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A thesis submitted to The University of Birmingham

For the Degree of Applied Educational and Child Psychology Doctorate

School of Education

The University of Birmingham

December 2015

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APPENDIX ONE: SUMMARY OF LOCAL AUTHORITIES' KEY DUTIES IN RELATION TO CYPS WITH HEALTH CONDITIONS, AS SET OUT BY THE STATUTORY GUIDANCE, 'ENSURING A GOOD EDUCATION FOR CHILDREN WHO CANNOT ATTEND SCHOOL BECAUSE OF HEALTH NEEDS' (DFE, 2013)

A Summary of Local Authorities' Key Duties in Relation to CYPs with health conditions, as set out by the statutory guidance, 'Ensuring a good education for children who cannot attend school because of health needs' (DfE, 2013a)

- To provide suitable full-time education (or as much as their health condition will allow) for CYPs of compulsory school age who, because of illness, would otherwise not receive suitable education.
- To provide this education as soon as it becomes clear that the child will be away from school for 15 or more days whether consecutive or cumulative.
- To liaise with medical professionals (and other relevant professionals) to ensure minimal delay in arranging appropriate provision for the child.
- To ensure that the education is of a good quality, as defined in the statutory guidance, 'Alternative Provision' (2013), allows CYPs to take appropriate qualifications, prevents them from slipping behind peers and allows them to reintegrate back successfully back into school as soon as possible.
- To address the individual needs of individual pupils when arranging provision.
- To ensure that CYPs with health needs have a good education, tailored to their needs, including social and emotional needs. This may involve for example ensuring that CYPs feel fully part of their school community, are able to stay in touch with classmates and have access to the opportunities enjoyed by their peers.
- To work constructively with schools, relevant agencies and parents to ensure the best outcomes for the CYP.
- To ensure that CYPs with health needs receive the same range and quality of education as they would have had at their home school i.e. access to a broad and balanced curriculum.
- To ensure that CYPs are able to access a suitable and flexible education appropriate to their needs. The nature of the provision should be responsive to the changing health needs/status of the CYP.
- To provide teachers with suitable training and support and be kept up to date with curriculum developments. They should also be given information regarding a CYP's health condition and the possible side effects of their condition and/or medication on the CYP.
- When reintegration into school is anticipated, LAs should work with the school (and hospital school, PRU/home tuition services if appropriate) to plan for consistent provision during and after the period of education outside of school. As far as is possible, the CYPs should be able to access the curriculum and materials they would have used if they were at school.
- To work with schools to ensure that the CYP is able to stay in touch with school while they are away e.g. school newsletters, emails, invitations to school events or internet links to lesson from their school.
- To work with schools to set up an individually tailored reintegration plan for each child. Involving e.g. reasonable adjustments that might be required.

APPENDIX TWO: INTERVIEW GUIDE AND INTERVIEWER SCRIPT

Interview Guide

1. Clarification of participation in research, consent and rapport building

- I thank the participant for meeting with me for the interview
- As consent will be gained prior to the interview (in a separate meeting), information about the research study will be discussed once more (recap) and any questions from the interviewee since our last meeting will be answered.
- Rapport building neutral conversations e.g. about their weekend, how their week has been, hobbies, which subjects they enjoy etc. This continues on from the rapport building in the previous meeting with the participant.
- Signatures will be obtained on the consent form if the CYP is still in agreement to participate in the research.
- CYPs' well-being (both physical and emotional) will be evaluated by asking a few short and informal questions prior to the interview taking place to determine whether an interview is appropriate for the CYP at that time. Scaling questions involving the use of a scale from 0 – 10 to ask children how physically and emotionally well they are feeling at the current time will be used. Based on CYPs' responses to these questions, I will judge whether it is appropriate for the interview to take place at that particular time.

2. Beginning of the interview

- 'Warm up' questions e.g.
 - Age + school year
 - Hobbies, what do you like doing?
 - Who is in your family? Who do you live with? Siblings? Do you get on with them?
 - Do your siblings have to come to hospital too?
 - How long have you been coming to hospital?
 - What brings you to hospital? Do you know the name of your condition?
 - How many times they come to hospital school each week? And how for long? Who comes? Who is the teacher? What do you do?
- Ask participant's preference re: people walking in/disturbing interview. Would they like to carry on? Would they like to stop? Both are fine – just let me know
- Would it be ok if we carried on later (on a later date) if necessary? Remember we can stop whenever you like, for break or if you want to stop in general.

3. Life chapters (McAdams, 1993)

- Participants are presented with empty 'storyboards' on coloured card, representing their life, starting from just before they first went to hospital (and thus first attended hospital school).
- Participants are invited to choose their preferred colours to make the storyboard more personal to them.
- Explanation of the framework will be explained to participants i.e. to facilitate discussion and to plot events in chronological order. The participants will be encouraged that this is *their* story and therefore if they wish they can draw pictures or write key words to illustrate their points. They will also be told about the variety of coloured shapes which can also be used in addition to the storyboard to facilitate discussion.

- Participants will be asked to imagine their own life as a story book (or a film). They will be asked to try to remember just before the first time they went to hospital up until the present time. They will be asked to divide up this book (or film) into a series of 'chapters', imagining the story book in the traditional format of 'beginning' 'middle' and 'end' with 'end' being in the future. Participants will be informed that they can have as many chapters as they like, ideally ranging from 2-8.
- They will be asked to think about the titles of the chapters and the age range/school year range that the chapter represents which can be any length of time. Participants will be given stickers to identify each chapter on the storyboard, after they have had time to think about this.

4. Critical events

- Participants will then be asked to tell me in detail about an important memory from each of the life chapters.
- I will then use appropriate follow-up questions and probes to elicit more detail and further information about these events, particularly in relation to the participant's thoughts and feelings about their experiences.
- Participants will then be asked, using visual prompt cards to identify along the storyboard:
 - A peak experience (best moment)
 - A nadir experience (worst moment)
 - A key turning point.
- If the participant feels it is appropriate, they will be given the opportunity to draw pictures on the storyboard to again facilitate discussion concerning their narratives.

5. Significant people

- Participants will be asked to think of 2 or 3 significant people or 'characters' who have had a significant impact on their life during this period, and to discuss these in detail.

6. Future scripts

- Participants will be asked to think about what their future might look like, including short-term future (in next academic year), medium-term (at next key stage transition point) and long term future (when adult).
- Discussion of future scripts is optional and this should be emphasised to participants, as participants may not have thought about their futures and/or predict it to be bleak. It is important that CYPs do not talk about this if they do not want to.

7. Reflections on their narrative

- Participants will be asked how they would summarise their whole experience of hospital and hospital school.
- If appropriate, the CYP will be asked if they are able to identify a particular theme that runs through the story.
- The CYP will be invited to think of a title for their narrative, thinking back to their narrative as akin to a book or a film. They will be encouraged that it can be imaginative, short, long, funny etc.

8. Debrief

- Participant will be asked if there is anything else they would like to tell me, of relevance to their narrative.
- Thanks for taking part in interview
- Participant will then be asked to reflect on how the interview experience was for them (positive/negative experience etc.) and how they have been left feeling afterwards.

APPENDIX THREE: FURTHER INFORMATION REGARDING CYPS' ROLE IN RESEARCH, INCLUDING NARRATIVE RESEARCH

The move away from researching 'on' CYPs to researching 'with' or 'for' young people has gained increasing popularity (Curtin & Murtagh, 2007). In particular, participatory research involving CYPs is widespread across many areas of social research, in which CYPs are researcher partners and co-designers of research projects (Daly, 2009; Akerstrom & Brunnberg, 2013; Torronen & Vornanen, 2014; Davies & Lewis, 2015). However, to fully involve CYPs in research in this way, there are a number of methodological and ethical challenges (Campbell & Trotter, 2007; Duncan et al., 2009), for example institutional contexts and significant power differentials between adults (researchers) and young people (the researched) (Duncan et al., 2009; Fox, 2013). Furthermore, researchers must beware of involving CYPs simply on a tokenistic level and must overcome the challenges of achieving benefits for both the CYPs and the research (McCarry, 2012; Petrie et al., 2006). There are also challenges regarding the definition of 'participatory' and the researchers' expectations for the level and nature of CYPs' involvement in research.

Using Curtin & Murtagh's (2007) constructions of the ways in which CYPs can be involved in research, I argue that my research is 'for' CYPs, rather than 'with'. Although participation of CYPs is often assumed to be a good thing (Fox, 2013), and I value CYPs' perspectives and voice, as clearly demonstrated by the nature of this research and its inherent values, participatory research was deemed inappropriate for my research. Fox (2013, p. 996) argues that "it is crucial to consider that individuals, groups and communities may have good reasons not to get involved". With respect to the CYPCCs in my study, participatory involvement was not only deemed practically improbable (due to CYPCCs being discharged from hospital), but also from an ethical perspective in placing undue responsibility and burden on CYPs who already have other larger priorities, such as their health. McCarry (2010) argues that CYPs face various (emotional and physical) commitments, for example national examinations, which was also a relevant consideration for participants in this study.

CYPs and Narrative Research

Research literature indicates that CYPs are capable of producing narratives. Research illuminates pre-schoolers' abilities to organise their memories of personally-experienced events into cohesive narrative reports, even from 40 months of age, a skill which develops with age (Fivush et al., 1995; Reese & Newcombe, 2004). It is therefore surprising that relatively few researchers choose to adopt the use of narrative research with CYPs. Furthermore, narrative interviews are not the only possibility for engaging CYPs in narrative research, and visual narrative research approaches which do not require much expressive language (for example using photographs), such as that used by Velasco et al. (2014) are becoming increasingly popular.

Despite narrative research often being conducted with professionals who work with children, such as Billington (2012), few researchers choose this option with CYPs themselves. Nevertheless, Blumenreich (2004) outlines her narrative research, involving a nine year old boy living with HIV. Despite some language difficulties, narrative research with this child proved to be an optimum choice of methodological approach for the study. In addition, other authors have effectively adopted narrative research (McNamara, 2013; Prior & Niesz, 2013) and narrative ethnographical approaches with CYPs (Hohti & Karlsson, 2014) to effectively address their research questions.

APPENDIX FOUR: INTERVIEW RESOURCES

Resources were used in the interviews for the purpose of engaging the CYPs in the interview process. Moreover, the resources enabled participants to express themselves in ways which may not have been possible without the resources, which was beneficial to the co-construction of narratives. The first photograph shows exemplary resources used, namely the storyboards and shapes, both in a variety of colours. The second photograph shows the completed storyboards by the 5 participants.



APPENDIX FIVE: PARTICIPANT INFORMATION SHEETS

INFORMATION SHEET FOR PARENTS/CARERS



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Dear Parent/Carer,

We would like to invite your child to take part in our research study. Before you decide we would like you to understand why the research is being done and what it will involve for your child. **Gabrielle (student researcher) is happy to go through the information sheet with you and answer any questions you have.** We'd suggest this should take about 10-15 minutes.

Talk to others about the study if you wish.

Ask if there is anything that is not clear.

The research study is about exploring the narratives of children who have experienced hospitalisation and have attended hospital school. The student researcher is a Trainee Educational Psychologist working at XXX Educational Psychology Service and this research project forms part of her qualifying doctorate in Educational and Child Psychology at the University of Birmingham.

Please read the following information which provides further details about the research project. If you are willing for your child to participate in this research, please sign the attached consent form and return it to [NAME OF STAFF MEMBER] at the hospital school. It would also be beneficial to discuss the research project with your child. Your child's consent will also be sought prior to conducting the research study.

What is the purpose of the study?

- The **aims** of the research are:
 - To understand children's personal reflections on key events throughout their period of hospitalisation and attendance at hospital school.
 - To understand the perceived impact of the hospitalisation and attendance at hospital school on young people and their families.
 - To add to existing research on this topic by illuminating the perceptions of these children's experiences in hospital and hospital school.

Why has my child been invited?

Your child has been invited to participate in the study because your child has had significant experience of hospitalisation and hospital school, and we are therefore very interested in their views on this. Having spoken to [Head of Hospital School], your child has been identified as meeting the inclusion criteria for this study. 4 or 5 other children will also be involved in this study.

Does my child have to take part?

Your child's participation in the research is entirely voluntary. It is completely up to you and your child whether your child decides to join the study. We will describe the study and go through this information sheet. If you agree for your child to take part, you will then be asked to sign a consent form. Your child is free to withdraw at any time, without giving a reason. This will not in any way affect the standard of care your child receives as this research is entirely separate.

What will happen to my child if they take part?

1. An **initial meeting** with your child, to which parents/carers are also invited, at the hospital school, which will last approximately half an hour. This will be for the purpose of explaining the research to your child and asking for their consent to participate. It will also be an opportunity for further questions about the research to be addressed and build rapport prior to an interview.
2. **One interview** lasting approximately 40 minutes which will take place in the hospital school with the student researcher, Gabrielle Pelter. If you or your child wishes, parents are also invited to be present at this interview. If necessary, the interview can take place over two or more sessions as a result of fatigue or your child's preference.
 - The process will involve an in-depth discussion about your son/daughter's experience of hospital and hospital school, asking your child to recall and reflect upon key events throughout this time and describe them in detail.
 - The interview will be audio-recorded so the student researcher can listen back to your child's story, as not everything can be written down at the time.
3. Your child will be involved in the research until the project is fully written up which will be December 2015 at the latest. However, their direct participation only involves the interview aspect of the study.

Please note: your child's medical treatment will be in no way affected by this research study as the research is entirely separate to your child's treatment.

What will my child have to do?

It will not be necessary for your child to do anything specifically in preparation for participation in the research study, for example keeping a diary, filling in questionnaires, dietary restrictions. If your child chooses however, they could reflect on their experiences of hospitalisation and hospital school prior to the interview taking place.

What are the possible disadvantages and risks of my child taking part?

Although no physical risk will be posed to participants, there is a potential risk that children may identify key events or incidents in their narratives that cause emotional distress. As a support mechanism, there will be a designated teacher identified beforehand to provide follow-up support to children if necessary.

This risk of emotional distress is further minimised by the student researcher's training in therapeutic and counselling skills as part of her educational and child psychology doctorate.

Therefore, the student researcher is in the position to conduct interviews in a sensitive manner, with empathetic listening and attuned responses to children's emotional needs. In the event of a participant appearing to become upset, they will be reminded of their right to pause/withdraw from the interview at any point. They will also be reminded of their right to choose not to answer certain questions or to fully withdraw participation from the research. If the student researcher deems that there is significant distress to the participant, the researcher will adjourn the interview in a professional and supportive manner.

Furthermore, the student researcher will ensure regular liaison with the staff at the hospital school (and parents/carers where appropriate), telephoning on the scheduled day of the interviews to check the well-being of the children prior to the interview.

What are the possible benefits of my child taking part?

Participation in the research study is not intended to benefit your child's medical health. However, the information gained from this study may have implications for improved educational professional practice for staff at hospital schools and professionals working with children who have experienced hospitalisation (including hospital school) and their families, for example mainstream school staff and Educational Psychologists.

The research itself may also have a direct, therapeutic impact on children, through the empowering process of being listened to during an in-depth interview, and having the opportunity to give their narrative accounts in meaningful ways to them.

What if there is a problem?

Any complaint about the way your child has been treated during the study will be taken seriously and addressed. Contact details are provided at the end of this Information Sheet for your reference.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact telephone number is at the end of Information Sheet). If you remain unhappy and wish to complain formally, you can do this. Details can be obtained from [NAME, Head of Hospital School].

NHS Based Research

In the unlikely event that something goes wrong and your child is harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the NHS Trust, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (if appropriate).

Will my child taking part in the study be kept confidential?

Yes.

Ethical and legal guidelines will be followed and all information about your child will be handled in confidence.

Your child's name will not be used in the writing up of the interview or in the final report. Anonymity is not guaranteed however as certain unique details in your child's story may mean that they are able to be identified by those who know them well. All efforts will be made to ensure that such identifiable aspects of children's stories are minimally reported. Pseudonyms will be used throughout the transcript and research report. Family relationships or professional roles may be referred to (e.g. sister, teacher or doctor). Every care will be taken to minimise the reporting of specific or unique case details that may reveal your child's identity. Your child will be able to inform the student researcher (Gabrielle), at any point, if there is anything that they would like to be left out. If, for any reason, the student researcher becomes concerned about your child's or others' safety and/or well-being, there is an obligation to pass on this information to the designated person within the school who is responsible for matters of this kind.

What will happen if my child does not want to carry on with the study?

Your child has the right to withdraw from the research before, during or after their contribution (within 7 days of the interview date), without giving any reason. Their medical care and legal rights will be in no way affected. This will mean that information provided will be removed from the project and erased.

Your child can choose to stop the interview (and the recording) at any time, without having to give a reason. Your child also has the right to withdraw any part of their interview. Your son/daughter can choose to exclude specific comments from the interview transcript and this will not be analysed. (It will not, however, be possible to erase this from the audio recording). If your child chooses to completely withdraw during or after the interview, the recording will be deleted from the Dictaphone immediately. Following the interview, all or part of your child's data from the research can be withdrawn for a period of up to 7 days, by contacting the researchers (see contact details below).

How will my child's data be protected?

1. **The audio-recording** – Your child's interview will be audio-recorded. The recording will be transferred to a password-protected computer and saved on an encrypted USB memory stick. Only the student researcher and the chief investigator will have access to this (as well as possibly examining researchers to check the research). The interview will then be permanently deleted from the Dictaphone (recording device).
2. **The transcript** - The exact words spoken during the interview will be typed into a transcript. No names (of individuals or organisations) will be used in transcripts: instead, pseudonyms will be used. Transcripts will be stored electronically as above. Any printed (hard) copies and hand-written notes will be stored in a locked cupboard. Only the student researcher and relevant individuals from the University of Birmingham will have access to the transcripts.
3. All data will be stored, in line with the Data Protection Act (1998), for a period of 10 years. After this time, all electronic data will be deleted and printed data will be shredded.
4. The data will only be used for the present study. It will not be retained for the purposes of future use in future studies.

What will happen to the results of the research study?

1. **Doctoral Thesis report** - This research study will be written into a 25 000 word doctoral thesis report for the University of Birmingham, which will be published, in full, online on the e-theses database. An edited, shorter version may be submitted to a peer-reviewed journal for publication, and findings from the study may also be disseminated at conference.
2. **Reporting to the hospital school** – Findings (including an oral presentation and a short written summary) will be reported to staff at the hospital school.
3. **Reporting to participants** – Children who participate in the research will receive a personalised debrief/summary at the end of the interview. Furthermore, participants will also receive personalised letters and certificates thanking them for their contributions to the research. In the letter that participants receive, a short summary of their data will be provided, making reference to individual quotations where appropriate.
4. It will also be possible for you to receive a follow up letter once the data has been analysed summarising key findings from the research project as a whole. Simply contact the research team (details below) if you would like to receive this.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by NHS Research Ethics Committee (REC) –Wales REC 4.

Further information and contact details

You may want further information on the following:

- i) General information about research
- ii) Specific information about this research project
- (iii) Advice as to whether your child should participate
- (iv) Who you should approach if unhappy with the study

Please feel free to ask the student researcher or chief investigator any questions on the above using the contact details provided below. Please note there will also be opportunity for questions and discussion with your child before and after the interview.

Contact Details	
Gabrielle Pelter (Student Researcher, Trainee Educational Psychologist) University of Birmingham School of Education Edgbaston Birmingham B15 2TT Phone: 0121 *** ** Email: *****@bham.ac.uk	Dr. Colette Soan (Chief Investigator, Academic and Professional Tutor) University of Birmingham School of Education Edgbaston Birmingham B15 2TT Phone: 0121 *** ** Email: *****@bham.ac.uk



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Part 1: Summary

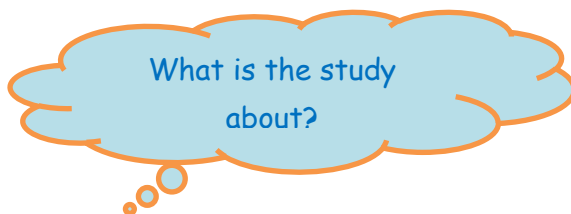
We would like to invite you to take part in our research project. Gabby (student researcher) is happy to go through the information sheet with you now and answer any questions you have. This will take about 10 minutes.

The research is about the experiences of children and young people, like you, who spend time in hospital and attend hospital school. We are interested in finding out about your story of how you have experienced your time at hospital and hospital school.

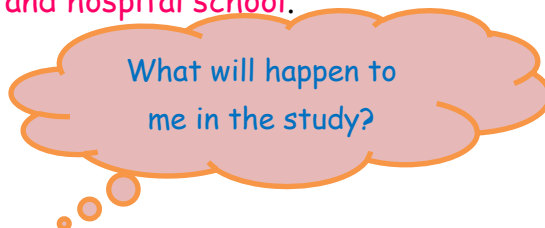
As well as making sure that you are happy to take part in this project, I have also asked for permission from your parents/carers.

If you are interested in this study, please read Part 2 below. It is entirely **YOUR CHOICE** whether or not to participate in the study.

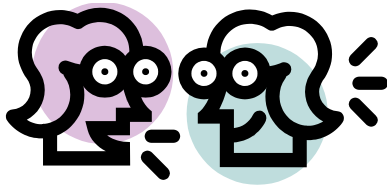
Part 2: Further Information about study



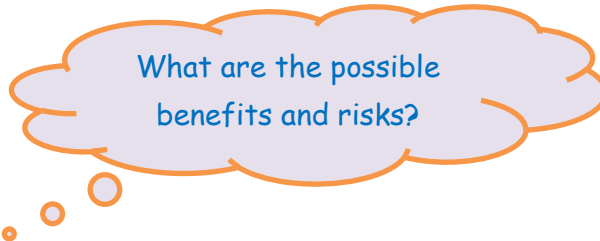
- ❖ Children's experiences of hospital and hospital school.



- ❖ A meeting with you, which your parents/carers can also come if you would like at the hospital school. This will last about 30 minutes. This will be to explain the research to you and ask for your consent to participate in the research. You can also ask questions about the research and get them answered and also to get to know you a bit better.
- ❖ One interview which will last about 40 minutes at the hospital school with the student researcher, Gabby. You can also have your parents/carers at the interview if you think this would help you feel more comfortable and relaxed. The interview can take place over two or more sessions if you would prefer or if you are becoming tired.



- ❖ The interview will be a discussion about your experience of hospital and hospital school. There are no right or wrong answers - it is your story that Gabby is interested in. The session should be fun and there will be opportunities for talking and drawing activities.
- ❖ The interview will be audio-recorded so that Gabby can listen back to your story, as not everything can be written down at the time.



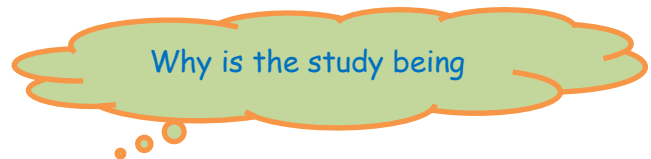
BENEFITS:



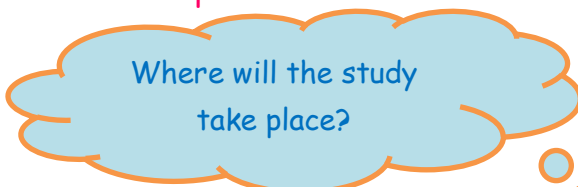
- Information gained from you and other children may help to improve how staff at hospital school work with children who go to hospital school.
- Talking about your experiences and having someone interested in your story and listening to you can make you feel good.

RISKS:

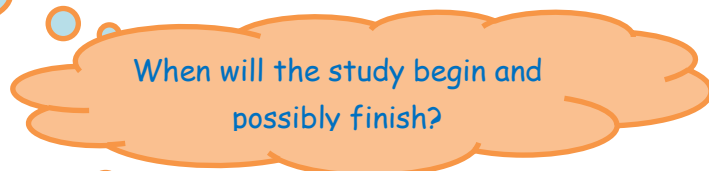
- No physical risk - you will not be hurt.
- You might think about things during the interview that cause you to become upset.
- To support you, there will be a teacher to provide follow-up support if necessary.
- You can also stop the interview at any point if you become upset and we can always rearrange the interview for another day if you would prefer.



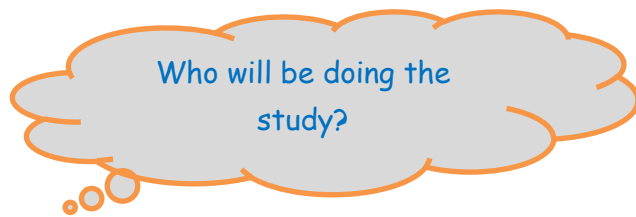
- ❖ To understand children's experiences of being in hospital and attending hospital school.
- ❖ To produce new research on this topic.



- ❖ Everything will take place at the hospital school.




- ❖ You will only be involved in the interview which will take place in June or July 2015.
- ❖ You will be involved in the research until the project is fully written up which will be December 2015 at the latest.



Please feel free to ask the student researcher (Gabby) or chief investigator (Colette) any questions using the contact details provided below.

<p>Gabrielle Pelter (Student Researcher, Trainee Educational Psychologist) University of Birmingham School of Education Edgbaston Birmingham B15 2TT Phone: 0121 *** ***) Email: *****@bham.ac.uk</p> 	<p>Dr. Colette Soan (Chief Investigator, Academic and Professional Tutor) University of Birmingham School of Education Edgbaston Birmingham B15 2TT Phone: 0121 *** ***) Email: *****@bham.ac.uk</p>
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 Please keep this Information Sheet in a safe place in case you want to read it again in the future.

INFORMATION SHEET FOR PARTICIPANTS (CHILDREN) AGED 11-16 YEARS



UNIVERSITY OF
BIRMINGHAM

School of Education



Part 1: Summary

We would like to invite you to take part in our research project. Gabby (student researcher) is happy to go through the information sheet with you now and answer any questions you have. This will take about 10 minutes.

The research is about the experiences of children and young people, like you, who spend time in hospital and attend hospital school. We are interested in finding out about your story of how you have experienced your time at hospital and hospital school. Your views are very important to us. Other children and young people aged 8 - 16 years will also be invited to take part in this project.

As well as making sure that you are happy to take part in this project, I have also asked for permission from your parents/carers.

If you are interested in this study, please read Part 2 below. It is entirely **YOUR CHOICE** whether or not to participate in the study.

Part 2: Further Information about study

What is the study about?



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- ❖ Children's experiences of hospital and hospital school.

What will happen to me in the study?

- ❖ A meeting with you, which your parents/carers can also come if you would like at the hospital school. This will last about 30 minutes. This will be to explain the research to you and ask for your consent to participate in the research. You can also ask questions about the research and get them answered and also to get to know you a bit better.
- ❖ One interview which will last about 40 minutes at the hospital school with the student researcher, Gabby. You can also have your parents/carers at the

interview if you think this would help you feel more comfortable and relaxed. The interview can take place over two or more sessions if you would prefer or if you are becoming tired.



- ❖ The interview will be an in-depth discussion about your experience of hospital and hospital school. There are no right or wrong answers - it is your story that Gabby is interested in. The session should be fun and there will be opportunities for talking and drawing activities.
- ❖ The interview will be audio-recorded so that Gabby can listen back to your story, as not everything can be written down at the time.

What are the possible benefits and risks?



BENEFITS:

- Information gained from you and other children may help to improve how staff at hospital school work with children who go to hospital school.
- Being part of the study may also help you personally. This is because talking about your experiences and having someone interested in your story and listening to you can make you feel good.

RISKS:

- There is no physical risk - you will not be physically hurt in any way.
- However, you might think about things during the interview that cause you to become upset.
- To support you, there will be a designated teacher to provide follow-up support if necessary.
- You can also stop the interview at any point if you become upset and we can always rearrange the interview for another day if you would prefer.

Why is the study being done?

- ❖ To understand children's experiences of being in hospital and attending hospital school.
- ❖ To produce new research on this topic.

Where will the study take place?

- ❖ Everything will take place at the hospital school.

When will the study begin and possibly finish?

- ❖ You will only be involved in the interview which will take place in June or July 2015.
- ❖ You will be involved in the research until the project is fully written up which will be December 2015 at the latest.

Who will be leading the study?

Please feel free to ask the student researcher (Gabby) or chief investigator (Colette) any questions using the contact details provided below. You are also able to ask any questions you may have before or after the interview takes place.

Contact Details

Gabrielle Pelter

(Student Researcher, Trainee Educational Psychologist)

University of Birmingham

School of Education

Edgbaston

Birmingham

B15 2TT

Phone: 0121 *** ****

Email: *****@bham.ac.uk

**Dr. Colette Soan**

(Chief Investigator, Academic and Professional Tutor)

University of Birmingham

School of Education

Edgbaston

Birmingham

B15 2TT

Phone: 0121 *** ****

Email: ****@bham.ac.uk



Please keep this Information Sheet in a safe place in case you want to read it again in the future.

APPENDIX SIX: INVITATION LETTER DISTRIBUTED TO POTENTIAL PARTICIPANTS TO IDENTIFY CYPs WHO STILL WANTED TO BE INVOLVED IN THE RESEARCH

After five interviews were conducted, a decision was made for ethical purposes, to provide the opportunity for other CYPs to participate in the study if they still wanted to. A letter was therefore distributed to these potential participants via hospital school staff.



UNIVERSITY OF
BIRMINGHAM

School of Education

30th June, 2015

Dear students, parents and carers,

My name is Gabrielle and over the past few weeks I have been conducting some research with students who have experienced hospital and hospital school.

I have now collected sufficient information and would like to thank all of you who have contributed to the research. I'm sure it will all be very useful for my doctorate thesis and it has been a great experience for me getting to know what it is like for children who have attended hospital school.

If you did not participate in the research, but would still like to, then please contact me or my supervisor via telephone or email (details provided below) and we can arrange a time that suits you, for an interview.

Best wishes,

Gabrielle

Contact Details	
Gabrielle Pelter (Student Researcher, Trainee Educational Psychologist) University of Birmingham School of Education Edgbaston Birmingham B15 2TT Phone: 0121 *** ** Email: ****@bham.ac.uk	Dr. Colette Soan (Chief Investigator, Academic and Professional Tutor) University of Birmingham School of Education Edgbaston Birmingham B15 2TT Phone: 0121 *** ** Email: ****@bham.ac.uk

APPENDIX SEVEN : FURTHER INFORMATION ABOUT INTERVIEW CONTEXTS IN THE PRESENT STUDY

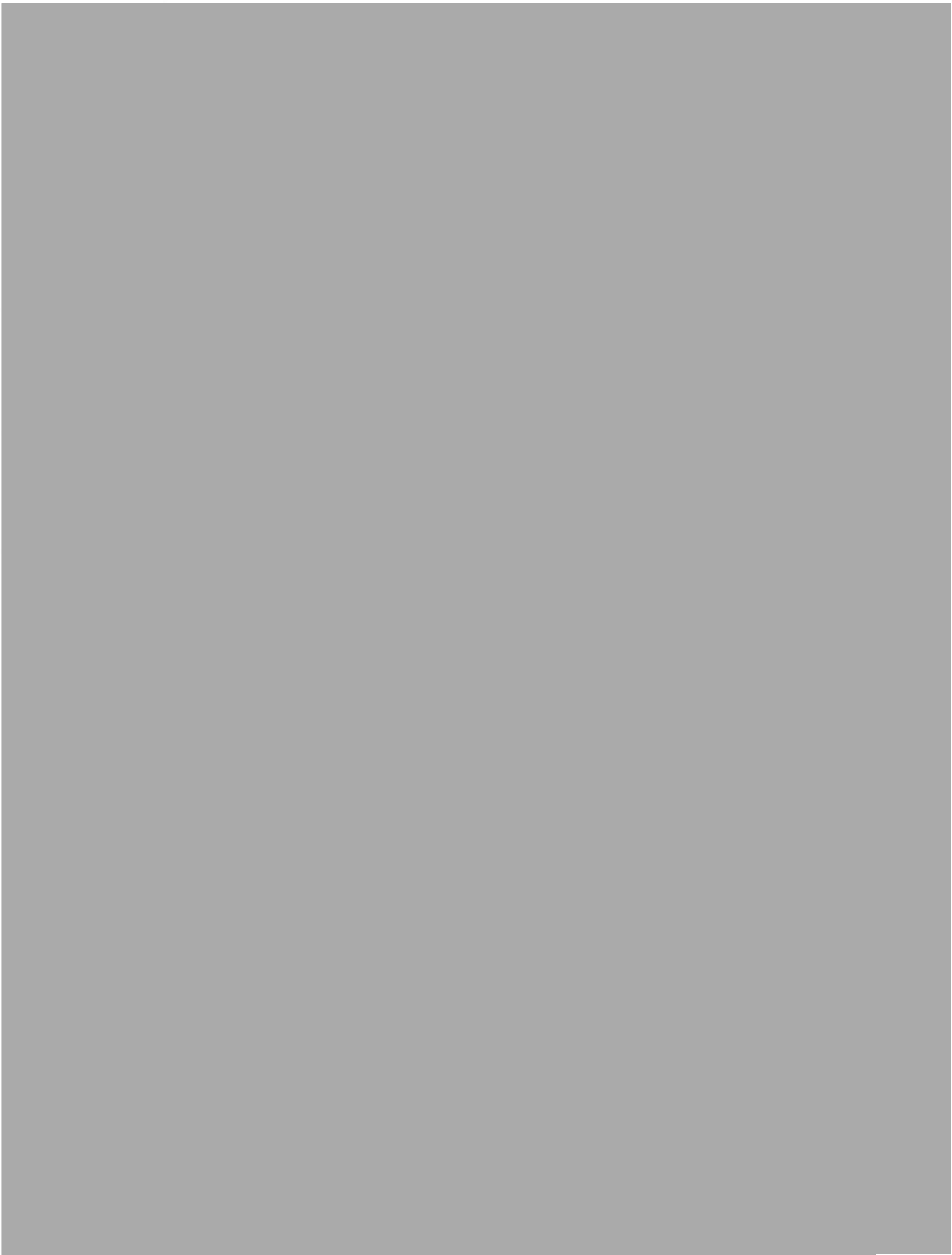
The five interviews were conducted in a variety of settings. Most interviews (four out of five) occurred on the hospital wards at the CYPs' bedsides, particularly as two participants were connected to dialysis machines during the interviews. For two of the bedside-conducted interviews, the curtains were drawn for additional privacy. All the wards were different in terms of layout, noise levels and the number of other people (in-patients, parents and healthcare professionals) on the wards.

One participant was interviewed in the 'young people's room' as she had finished her dialysis at the time of the interview and was able to move around freely. The 'young people's room' was perhaps the most conventional interview location as it was private and quiet. Furthermore, it appeared to be a room which CYPs could access leisure activities and entertainment such as books, films, a Wii and an Xbox. The room was small and brightly coloured with comfortable chairs. As this room was selected by the participant herself, it is possible that this was a room in which she felt at ease. By contrast, all of the (four) wards on which the other four interviews took place, were not private and were almost always very noisy (talking, screaming or medical machines), with varying numbers of other people on the ward.

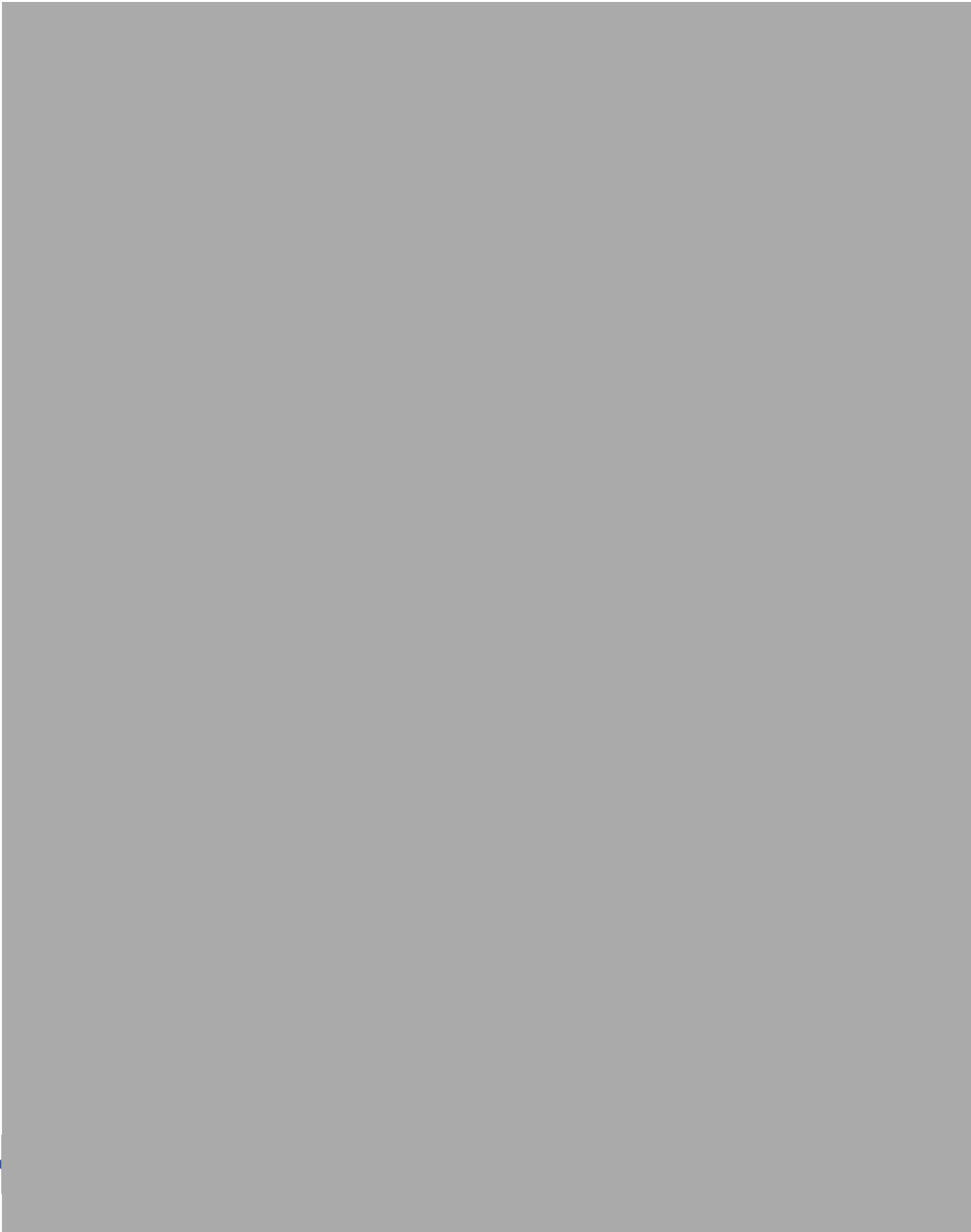
The variety of interview contexts is not unique to social research in hospital settings and Coyne et al. (2009) report similar experiences. Like Coyne et al. (2009), the conduct of interviews in communal areas resulted in numerous interruptions for the present study, for example healthcare professionals checking wellbeing and giving medication and parents interrupting with their own views and to provide lunch. Although most of these interruptions were minor, some involved longer disturbances, and as a result the productions of narratives were often also disrupted with regard to the flow of the conversations. As such, time was then needed to reconsider what exactly was being discussed before the interruption and so on. Interruptions never impacted on participants' participation, which may be because the participants are accustomed to the disruptions in the hospital environment (Coyne et al., 2009). Disruptions by medical professionals may also be indicative of a lack of respect for children's right to be heard and to be involved in research (Coyne et al., 2009).

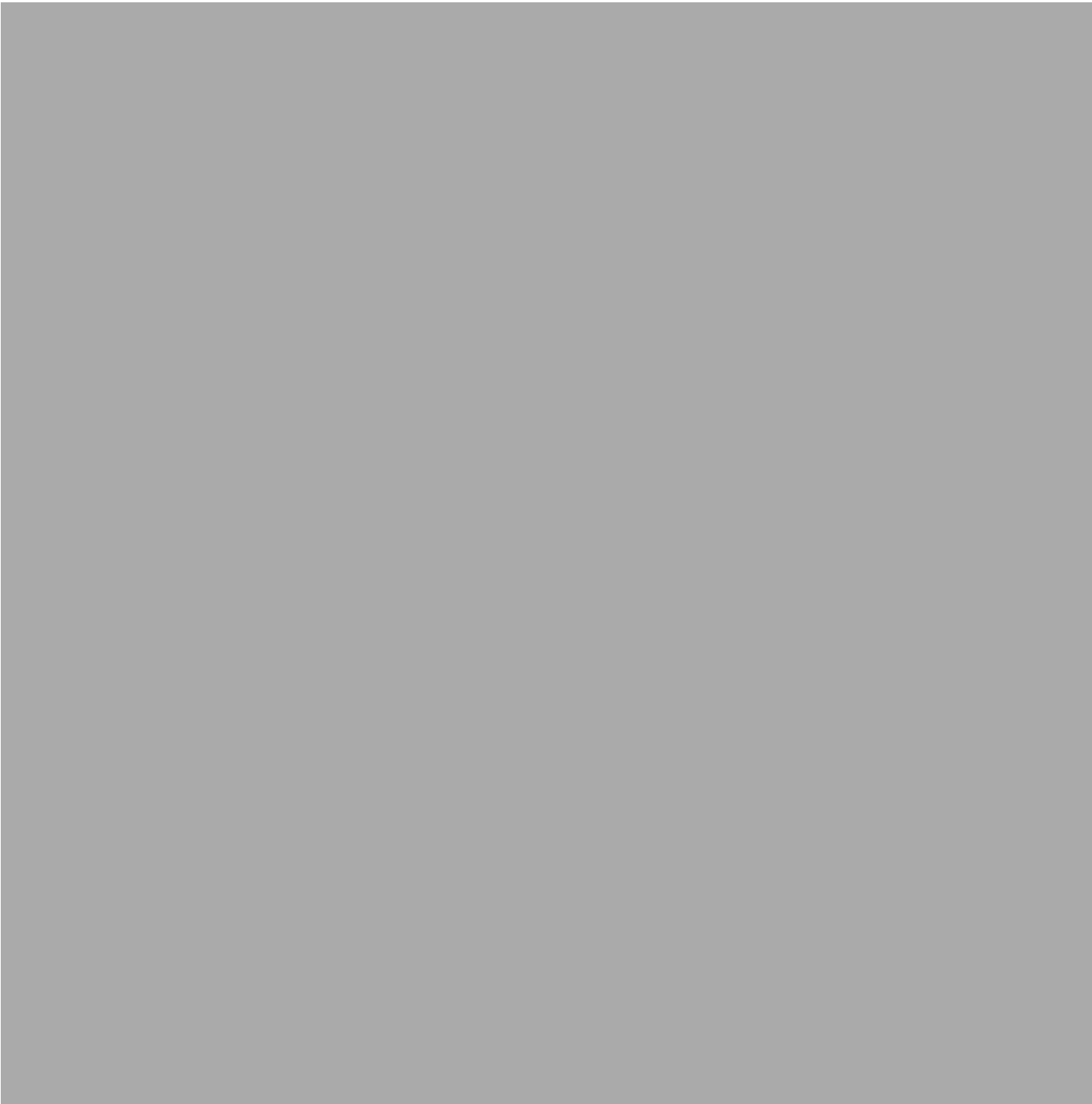
Despite my efforts to 'fit in' around the CYPs' schedules, which in reality meant a lot of waiting time (such as for a student to finish his physiotherapy session and long periods waiting for hospital school staff to become available), this was considered the best approach to take in order to guarantee the collection of data in a somewhat unpredictable and hectic hospital environment. Despite this, interviews were cancelled on several occasions and improvisations were made.





**APPENDIX NINE: CONFIRMATION OF FAVOURABLE ETHICAL OPINION FOR THE CURRENT
RESEARCH FROM RESEARCH ETHICS COMMITTEE (REC) (MAY 2015)**







APPENDIX TEN: AMENDMENTS MADE TO PARTICIPANT SELECTION CRITERIA

Some alterations to the participant selection criteria were judged necessary after meeting with hospital school staff and the clinical lead (consultant oncologist in the hospital). These are outlined in Table A1 below.

Original criteria	Altered criteria	Explanation
1. Aged 8: 14 years (Inclusion)	8:0 to 16:11 years	Hospital school staff indicated that expanding the age range was advisable due to the availability of CYPs who were hospitalised at the time.
2. Children with Special Educational Needs (as defined by the Special Educational Needs Code of Practice (DfES, 2001) (Exclusion)	Children with Special Educational Needs (as defined by the Special Educational Needs Code of Practice (DfES, 2001) with their primary special educational need under the categories of communication and interaction; cognition and learning or behaviour, emotional and social development.	Having discussed this with my supervisor, it was considered appropriate to be more specific with the type of Special Educational Need, to increase transparency for hospital staff who were involved in the identification of participants. Furthermore, the Head of the hospital school indicated that under the original selection criteria some CYPs who could potentially participate in the study, were excluded due to their medical needs. Therefore, this particular exclusion criterion was made more specific.
3. Children with life-limiting conditions	Children with 'life-threatening' conditions	The clinical lead (consultant oncologist) advised that the terminology was changed to more accurately reflect the likely participants who would be participating in the research.

Table A1: Amendments made to participant selection criteria

APPENDIX ELEVEN: APPROVAL FROM RELEVANT NHS FOUNDATION TRUST

In addition to gaining ethical approval from the Research Ethics Committee, it was also necessary to obtain approval from each of the NHS Foundation Trusts (one in the current study) at which the research would take. Specific details from the letter have been obscured and logos removed, to maintain anonymity.

Research and Development Office

Direct Line: [REDACTED]

Our Ref: [REDACTED]/[REDACTED]/R&D Approval
16th January 2015

Dr [REDACTED],
[REDACTED] Children's Hospital NHS Foundation
Trust [REDACTED]

Dear [REDACTED],

Re: [REDACTED] [REDACTED] Hospital NHS Foundation Trust R&D Approval
Study title: In Hospital but Not Forgotten: An Exploration into Children's Narratives about their Experiences of Hospitalisation and Hospital School
REC reference: 14/WA/1203 161655
IRAS project ID: 161655

Thank you for complying with the [REDACTED] [REDACTED] Hospital NHS Foundation Trust's R&D approval process. I am now happy to approve the above study. You will note from the Research Ethics Committee (REC) approval letter dated 12 December 2014 that the favourable opinion is subject to obtaining management permission or approval at each host organisation prior to the start of the study. This letter constitutes that approval.

Approval of the study is subject to the following conditions:

1. That you inform the R&D Office and the REC of any significant protocol amendments, sending copies of correspondence with the REC and also sending us copies of your REC annual progress and safety reports
2. That you notify the R&D Office and the Governance Support Unit of any adverse events arising from this piece of research
3. That you provide the R&D Office with interim reports as requested by the R&D Office and a final report of your research
4. That you conduct the research in conformity with the Research Governance Framework and with clinical trials legislation where applicable.

Yours sincerely

[REDACTED]
Head of Research, Development and Innovations

APPENDIX TWELVE: PARTICIPANT CONSENT FORMS

INFORMED CONSENT FORM FOR PARENTS

Title of the Study: **In Hospital but Not Forgotten: An Exploration into Children's Narratives about their Experiences of Hospitalisation and Hospital School**

Name of Chief Investigator: Dr Colette Soan, Academic and Professional Tutor, University of Birmingham.

Name of Student Researcher: Gabrielle Pelter, Trainee Educational Psychologist, University of Birmingham

If you agree for your child to participate in this research, please read each statement below and indicate your response with your initials in the appropriate box and sign below to give your informed consent.

Yes	No	
		I have read and understood the information sheet (Version 1.0 6/9/14) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
		I understand that my child's participation is voluntary.
		I understand that my child is free to withdraw before, during or after their contribution (within 7 days of the interview date) without giving any reason, without any medical care or legal rights being affected. This will mean that information provided will be removed from the project and erased.
		I understand that what my child says will remain confidential and the final report and associated publications will not include any names or information that can identify my child.
		I understand that what my child says is confidential unless it puts them or others at risk.
		I understand that relevant sections of my child's interview data during the study may be looked at by appropriate individuals from the University of Birmingham.
		I understand that the interview forms part of a University of Birmingham postgraduate doctoral research project.
		I consent to the interview being audio recorded.
		I understand that in line with the University of Birmingham's policies on research, the student researcher will store the interviews (audio and transcribed) in a secure location (password-protected computer and a locked cabinet), and will securely keep the transcribed interviews for up to 10 years after completion of the project, at which point they will be erased and shredded.
		I consent to my child taking part in the above study

Name of Participant

Date

Signature

Name of Parent

Date

Signature

1 original for parent, 1 copy for study file.

INFORMED CONSENT FORM FOR CHILDREN







Title of the Study: **In Hospital but Not Forgotten: An Exploration into Children's Narratives about their Experiences of Hospitalisation and Hospital School**




Name of Chief Investigator: Dr Colette Soan, Academic and Professional Tutor, University of Birmingham.

Name of Student Researcher: Gabrielle Pelter, Trainee Educational Psychologist, University of Birmingham

Dear [NAME]

Please make sure you have read (or listened to) the Information Sheet before filling in this form. Please read the statements below and put your initials in the boxes if you agree with them.

	I have read (or listened to) and understood the Information Sheet (Version 1.0 6/9/14) for the above study.	
	I have had time to think about the information, ask questions and have had these answered.	
	I confirm that I am choosing to take part in this project and have not been pressured.	
	I understand that I can withdraw from this project at any time without giving a reason and my medical care and legal rights will not be affected. If I withdraw, my interview recording will be destroyed.	
	I understand that I do not have to answer any questions during the session(s) that I do not want to or feel able to.	
	I understand that the things I talk about in this project will be written in a report. My name will not be used in the report. Extracts from the recordings may be used as quotes to illustrate certain points in the report however no actual names will be used.	

	I understand that the session(s) will be audio-recorded so that there is a good record of what was said.	
	I understand that the interviewing recording will be heard by the student researcher (Gabrielle Pelter) and relevant sections may be looked at by some individuals from the University of Birmingham. Typed up interviews (transcripts) will be stored in a locked cabinet in the student researcher's office.	
	YES!!! I agree to take part in the above study.	

Name of Participant

Date

Signature

Thank you for your time reading and completing this form ☺

Please return it to Mr [NAME, Head of Hospital School] or personally to me during
our meeting now.

Yours sincerely,

Gabby

(Gabrielle Pelter, Student Researcher & Trainee Educational Psychologist)

1 original for participant, 1 copy for study file.

APPENDIX THIRTEEN: EXEMPLAR TRANSCRIPT

An extract from Rose's transcript is presented here for purposes of transparency and clarity.

Transcript 4 – "Rose"

I didn't want to go to hospital but I didn't quite understand *why* I was taken into hospital. But I just felt so poorly I kind of knew that I needed to

Yeah. Ok so this one is from 9 to 10.

Yeah

So can you tell me an important memory from this one

That one's getting back that's getting back home yeah that one's getting back home

That's 10 to 11?

Yeah

So what's an important memory from that one then?

So when I was the night I was poorly and that one was getting back home as well yeah

Yeah

Yeah it was. I'm getting confused [laughs]

That's ok there can be a bit of from when you were 9 to up here

Yeah so I was getting back home getting better and feeling alright but then I still had chemo but I was still alright and I think the main one when I was 11

Yeah

Was going skiing

Going skiing

Actually I was 12

So in this one?

Yeah I think I was 12

So you went skiing? That's fantastic – that's a good important memory isn't it

I went skiing at Christmas and we went all we went to we went to Switzerland with all my family

Wow

Yeah cuz my uncle and aunt and two cousins live in Switzerland so we all went to their house

That's handy learning German for them isn't it

Yep

[Both laugh]

They speak English but

But they speak German as well?

Yep

That's brilliant. And what's an important memory then from this one? When you're 12 – this last chapter when you're 12?

Being in hospital this is now so being in hospital and being a bit bored really because I still feel sick but when I don't there's not much to do

And what do you mean by there's not much to do?

Like at home if I was bored and it was a Saturday or a Sunday we could go for a walk or cuz there's a park near our house so either go to a park, we could go and have a picnic somewhere, we could paint, we could draw, but you can't really do all of that here. You can draw but it's not like there aren't really nice pens or there's not really enough space as well cuz that is the only really surface except that there's the top ledge there that can come down but then there's not really very much room

No. for drawing. Ok so now that we've thought of an important memory from each of your chapters which is brilliant I'm going to ask you to think of the best moment not from each one but from all along there so from when you were 9 years old. Oh I forgot to ask about hospital school. So when did you go to hospital school? Or when did they come to you rather?

When I got transferred into

[name of hospital]?

No that's not that one () [name of hospital] then to [name of current hospital] and in that one when I was in [name of current hospital]. So I went to [name of first hospital], then I went to [name of next hospital] because they made me go to [name of city] and when I was in [name of city] here, down there I went to there was a teacher who was Mum used to babysit the teacher [laughing] when she was little and all of our family knows her she used to live near us. [name] used to be a teacher here for primary school I'm not sure if she did secondary school

But she taught you when you were in primary?

Yeah

Was that for Year 5 then? or Year 6?

Year 4, 5 and 6 really I wasn't really at school much but I did get back to school but I only went in for random days

Ok when you were feeling well enough?

Yep

Ok

[Nurse returns. Gives Rose eye drops and talking to her about it]

Ok so what I was going to ask you was about your *best* moment

Oh and school. I was then there and when I was transferred back to [name of hospital]. Ah so that's a big bit because in all of that

All of when you're 9? And in chapter 2?

I was sent into hospital, transferred into [name of city] and then transferred *back* to [name of original hospital]

Ahh. So that's why you were getting confused it's actually quite confusing

[both laughing]

It was

And then transferred back

Yeah

Ok

When I was transferred back I had some school from someone called [name] at [name of original hospital]

Ok so you've been to hospital school there and here?

Yeah but she didn't come much because she was she only knew I was there about half of the time cuz I didn't feel well there at all. But yeah

Ok. So what I was gunna ask was about your *best* moment. So along the whole of the time that you've been at hospital and about hospital school so all of these different chapters when what has been your best moment? And you can choose a shape and we can stick it along whichever chapter it comes in. so I've got stars I've got circles , hearts, diamonds

That's *hard*. The best one would be being better being fine but then the next best one would be being getting home cuz after so long in hospital. But my next best one would be being fine. So I'm not sure.

So you've got 3 at the moment? Should we put them all as best moments?

Not sure

Or have you got a particular one that's *even* better cuz we've discussed those 3 now

I think that one because that was me getting fine and back to normal

Brilliant. Do you want to pick a shape?

Mmhmm. What shapes are there?

I've got hearts, circles, triangles, diamond shapes

A star please

A star? Any colour?

Random colour

I've got pink – you wanted pink earlier

Yeah

And I should have some glue here. So you want me to stick it in chapter 5?

Yes please

Could you tell me a bit more about that best moment?

I'm I went cuz we before I got poorly we used to go to Switzerland twice three times a year at all the holidays to see my cousins and my cousin is 2 and I think my cousin was born while I was poorly, yeah my cousin was born when I was poorly so we used to go and see them *loads* and but suddenly we couldn't see them so they have been to visit but it's not like the same when they come to visit

Yeah

Cuz it's *really* nice going to Switzerland as well. We go on an aeroplane and we go there and we do loads of things there and skiing and stuff and going skiing I've wanted to do for ages so that was good.

That was a good moment for you

Mhmm yeah

That's brilliant. And now the next one is, is there a worst moment? So from all of these chapters that you've got from the time you've been in hospital and the time you've been going to hospital school as well is there a worst moment?

It would either be being poorly the first time or the second time but I think I'm going for the second time because I (thought I) was better and then I got poorly again

Yeah. And what was that like for you?

Sad. Cuz I kind of before it happened because when I got poorly the second time I was fine I went home on the bus it was the second time I'd gone home on the bus at school cuz I didn't get the bus much and when I got home it hurt *there* which was the same place so I thought. I kind of knew before it had happened that it was

You had a bad feeling?

Yeah. It was probably likely to be the same kind of thing

[Mum: I was greeted with 'I need morphine, I need to go to hospital I bet we're gunna end up in [name of city]']

Yeah

[Mum: she can usually tell before anything happens]

Yeah we got home in the car home I was like it hurts when I breathe a bit but I thought oh it must be because we pass loads of fields on the way back from school it's like oh it must be that and then we spent a long time at my friend's house cuz the bus dropped us off there and I was thinking yeah it's starting to hurt quite a bit. I remember when we got home Mum made pasta for dinner cuz I remember that [laughs]

You can remember all the details can't you

Yeah. I remember I was like this is really really hurting I can't do anything this is really hurting. And then it started to *really* really really really hurt and then we just had to go to bed. I had a I think I had a bath cuz it was hurting so much. And that

[Mum: () you just pulled your neck a bit up]

Yeah and then I couldn't get to sleep all night and then at 2 o'clock I ended up going to A & E it hurt so much and we had to phone the ward as well cuz we didn't know cuz I was better but we didn't know I wasn't fully better if I could go to the ward or not. So we went to A & E eventually and they did a heart ECG and then and then they did an x-ray and then

[Mum: an ultrasound]

Yeah an ultrasound and then they said you need to go to ward so we did and my consultant was on the next day and gave me morphine and lots of other painkillers and then she kind of said you need to go to [name of city] and she said she kind of whispered to Mum, Mum said is it like [name]. [name] is another boy here he is relapsed as well quite similar timing and then she said probably and my Mum kind of knew and then we got sent here

Yeah. That's all happened quite recently hasn't it?

Yeah

Shall I take one of these? Or do you want to pick one and I'll take it out if you want

Circle

APPENDIX FOURTEEN: RULES AND NOTATION SYSTEM USED IN THE TRANSCRIPTION STAGE OF DATA ANALYSIS

As literature indicates, explicit transcription rules and a well-specified notation system are necessary to increase the trustworthiness of a research project (Polkinghorne, 1988). Table A2 outlines the rules and notation system used in the transcription stage of data analysis. It is to be noted that standard punctuation was added to the transcription where appropriate (for example question marks, commas, full stops and exclamation marks) which represent standard English grammatical rules.

Table A2: Transcription rules adopted for transcribing interviews during data analysis processes in the current study

Notation	What notation represents
Italicised words	Words said with additional emphasis
Words in red	Represents an interruption, which is unrelated to the co-construction of the narrative, for example medical professional checking machines/changing fluids/examining CYPCC or parent
Parentheses	In accordance with transcription notation suggested by Atkinson and Heritage (1984), parentheses indicate doubt about what has been said. An example, '(but)' is representative of my doubt that although I think that the word 'but' has been said, it is not a certainty. When first or last letter(s) have been used, for example (s-), it indicates that the word was not heard in its entirety but that it may have begun with the letter 's'. When parentheses are empty, i.e. (), this indicates that the word or words were inaudible (for example due to significant background noise or quiet volume of interviewee) or unintelligible (e.g. due to pronunciation as with Suzan who has English as an additional language, or when a word may have been said very quickly).
Words in black	Words said by myself, as researcher and interviewee. These have not been omitted to highlight my role in the co-construction of the narratives
Words in purple	Words said by interviewee
Words in blue	These are words said by the participant's mother in Interview 5. Some of her comments were regarded as an active contribution to Sajid's creation of his narrative as she was actively involved throughout the interview. Therefore, these words were not considered an 'interruption' to the construction of narratives, as were with other disturbances by other people in the various interviews
Words in green	These indicate actions, such as when the participant or myself were writing, laughing, getting up from a seated position and so on.

APPENDIX FIFTEEN: EXEMPLAR ANALYSED TRANSCRIPT

An extract from Sumayah's transcript is presented here in order to demonstrate how transcripts were analysed during data analysis processes. Comments relating to event and experience narratives were highlighted and codes were identified. Superscript numbers represent the coordinating code number.

Transcript 3 – "Sumayah"

Six when I got my but afterwards I realised and I was in the hospital for about two three weeks but I just remember it all. I was I used to have this thought when the door was closed and the curtains were drawn that everyone outside is playing catch in the corridor¹² and a giant rabbit? And giant animals. And that's when I beat Dad for the first ever time playing Monopoly¹³. It was my first time playing Monopoly. I remember me and my brother made chocolate covered rice crispies and we put the bed on the highest setting and Mom walked in on us. The cleaner gave my chocolate bunny to my brother and he decided to eat all of it and not give any to me

Course

I received loads of gifts from everyone I remember having loads of teddies¹⁴.

All around your bed?

I remember having this new Game Girl type of thing¹⁴. I used to have this cup a slushy cup but basically a reusable one with a like a cool straw in it¹⁴ and I remember throwing stuff on my Mom's bed¹³ when she used to sleep. I remember the pillows had feathers in them never forget that and I even remember the painful parts like when they took out my drain¹⁵. I cried so much that day. It was really painful¹⁵.

So that's what happens when you receive a transplant they have to take out

They insert a drain so while you're asleep when you wee, you just it just goes into the drain. And it also helps you because when you're unconscious like on the theatre bed like if you wee it won't make a mess⁷

Yeah that makes sense doesn't it

Yeah

You were saying that that's really painful when they take it out after when you're awake

Yeah because they use like a sharp point thing and they took out the stitches and they pulled it and just the thought of it makes you feel sick¹⁵

Yeah

I had it done quite recently when I got my kidney taken out again and yes again, and afterwards I just felt really hot and flustered and I just felt sick¹⁵

Yeah. So that receiving your transplant then for you was a really really big important memory in that time wasn't it

Yeah. And there was also bad parts, after the transplant. Like having chest infection. Meeting the Playworker [name of Playworker] for the first time like we met and she used to always talk to me and we

played Scrabble when she was pregnant. She passed away. She was ill but she was one of the best Playworkers ever^{16 and 23}. We had I think we had 2 Playworkers after that. They just gave up really and quit¹⁶ and we got our new Playworker [name of another Playworker] she's been here for quite a while now. I was admitted on her first day at work and we've got such a nice relationship¹⁶. It's like everyone from the school and from the Playworkers they've just got this relationship and everyone knows everything in a good way

Yeah. That's really good. I'm probably going to ask you a bit more about that in a bit. When I ask about important people. Because it sounds like you've already mentioned a couple of important people haven't you. That's good. Brilliant. So that last chapter then, where it says 14 years old to the present, can you think of an important memory from that time. Something that sticks in your mind

14 year old yeah what's been happening since 14 year old. I got my Xbox¹⁴. I remember that. That was (). I spent all afternoon testing out all my new games. And had all the modern games all the modern updates. I even had Xbox Live Gold. And just felt amazing.

Yeah definitely write that one then. Definitely. That sounds like it was very important to you. As I said there's no right or wrong answers so that's brilliant. I was going to ask though if there's anything that you remember from hospital or hospital school as well

Yeah

That's been an important memory that you can add to that as well

[Sumayah writing]

Could you tell me what that one says?

When I was like about 10 I used to go to the hospital school and I remember seeing it for the first time and I was like why hasn't anyone ever told me about this

[I laugh]

It was bright, it was colourful, it was fun⁸. And I just thought do you know what I'd love to come here for school instead of my school. I just loved it everything about it I love it like the teachers they were super friendly. You'd have to come back for lunch and then you'd go back. I used to look forward to school. You'd meet other people from other wards and just interact with different people¹⁷. And just gives you a place where you can just be at school and not need to worry about losing out on education^{6 and 8}

Is that something that you would worry about then?

At the time, no – I was glad that I was out of school me being 10. But now that I think of it I'm really glad that we've got teachers here that come onto the wards and contact you and learn with you⁶. Well not learn – teach you. Because that is a major help nowadays. Like I've been doing my GCSEs and my teachers that come here have helped me out a lot, especially [name of hospital school teacher]. I remember going to the high school as well

[Sumayah writing]

What's the high school?

I went to the high school and it looked really different

So this is the high school in the hospital?

Yeah and there was this kid which talked about always going to the shops and kissing girls and I was like he's lying. I used to go with my friend [name of student] to the school¹⁷ I went when it was Chinese New Year I think /last year I went and it was Chinese New Year and they built a trolley dragon and It was really fun⁸ it was very more hands-on than actual work and they always know how to make the work and the lessons more fun⁸. Like they don't pressure you to work hard they pressure you they don't pressure you but they help you achieve your possibilities just by not pressuring really¹⁸.

So do you think that's helped with your exams then?

Yes.

Brilliant. So you've got your important memories there. 14 to the present. So getting your Xbox, going to the

Receiving a quad bike¹⁴

Oh did you? That can go down there definitely – not many people I know have quad bikes.

[Sumayah writing]

Was that for your birthday?

Yeah. My Dad goes to me if you stay well I'll get you one for your birthday but we was looking all over the internet and very high prices – 200, 300 was cheapest and Dad wanted something that he knows that I'm safe on¹⁹ and all of them were from China and they take ages to come and you're not sure what you're going to get and within a stroke of luck I got one of the most powerful 50cc bikes , one of the fastest in the UK and it only cost me well it cost me less than £100

Woah. Bargain. Does your Dad worry about you being safe then?

He does but he's always with me when I use it¹⁹

Yeah. Ok so what I'm going to ask you to do now, we might need the shapes for this bit, now that you've thought of an important memory from each of the chapters what I want you to do is to think of the *best* moment along the whole story board. Do you want a shape? That you can put best moment on?

Yeah sure

What shape would you like? We've got diamonds, triangles, circle, stars

Circle please

Circle. Any colour?

Any. Not fussed. Oh got one for the last one – going London for the first time

Oh brilliant. Were you going there for any reason or was it just for a nice trip away?

It usually (m-) trips and [name] and [name] tend to come from the school. Or [name], [name] has left now.

Oh so was it like a school trip?

Yeah kind of. It was with the ward

So it was like a hospital trip?

Yeah and they all one of them always comes and I love it when [name] comes because she's such a happy person and she like she makes the atmosphere very nice place²⁰

And what's [name]'s job?

[name] is a teacher for the younger kids, [name] is a Teaching Assistant, [name] was a high school teacher, but she retired. She was one of my teachers before I even started learning here on haemo. She used to when I was admitted she used to come and she'd encourage me to go to school and she'd do work with me and before we left, just for fun, she said let's do a cooking lesson and we made chocolate chip cookies. She was an English teacher but all round fun person²⁰.

[Nurse comes into room: Sorry to interrupt. Just going to do Farah's presents and wondering if you wanted to be there.

Sumayah: Yeah. 2 minutes.

Nurse: 2 minutes? And then come through then?

Me: Yeah we can stop it and then yeah. Not a problem.

Nurse leaves]

We can stop it and then you can go out if you want

Ok

I've got a few more questions but I could always press pause couldn't I?

Ok. Thank you

No problem because I know it's quite an important obviously I didn't plan it to be like the last day and that's just the way it happens sometimes and I don't want you to miss out obviously

Ok

So do you want to go now and I pause things and then you come back

Yes please

Yeah we'll do that. And then I was going to ask you about your best moment, I'll ask you that when you come back

Thank you

No problem. And get yourself a drink or any food or anything if you want and you can bring it in here if you want

Thank you very much

No problem. I'll see you in about 5 minutes or so?

Yeah should be

Yeah

[31:40 – 36:00 - Sumayah is out of room]

[Sumayah knocks on door]

Hey

Can you open the door?

[I get up and open door]

Thank you

No problem. How was it?

It was good.

Was she crying?

No

No she was alright? She was just crying when your Mum came wasn't she?

Yeah because we've known each other around. Since Ward 1 has been here we've known each other. We've been really close we've been on trips together. We've been basically next to each other. We've even stayed up pretty much all the night in hospital¹⁷ and

Chatting?

Yeah. She's like more of a sister slash best friend and I will miss her¹⁷

Is she your sister slash best friend out of all the friends you've got

Yeah

Yeah pretty much? You've spent a lot of time together?

Yeah

So how long have you known each other then? Since how old were you?

I think it's been about 4 to 5 years we've known each other¹⁷

That's quite a long time isn't it

Yeah

But as your Mum said, you will see her and she'll come round to yours and you can speak to her on the phone

Yeah

And what hospital are you going to?

I'm staying here

You're staying here.

Yeah they're gonna keep me for a bit longer² than the other patients because there's more than just one thing to deal with with me⁴

Ok. So my question was going back to the like what was your best moment? So out of your whole story board, what's been your best moment, thinking about hospital and thinking about hospital school, what's been your best moment? You can stick in anywhere along there you can just put best on there, you can stick it anywhere along there

I'd have to say

You can give me one of those things or something else

Going to Reception I just loved that when I was little.

[Sumayah writing]

I can do if you want

Yeah

Thank you too many things. Got too much stuff! Ok so why did you pick out that then as being your best

It's just where I could be me and not need to worry about anything, just have fun⁸.

Do you feel like after that you haven't been or?

I have been having fun but at the same time like I've gone older I've known what's been going on. And started putting the pieces together and needed to take a bit more notice⁷.

So could you tell me a bit about, as you've got older, you've become more aware of things

Yeah

And do you think that has been a positive thing or a negative thing?

Yeah

A positive thing

Because I can understand things now. But it's a positive and negative. I can understand things I know what to do⁷ but sometimes when the negative is sometimes you just wanna shut down and pretend you don't know what they're on about and no-one likes bad news¹⁰

Ok. So going on to the next thing, so that was your best moment, is to think of your worst moment. Do you want me to give you a shape for this?

The worst moment when I was that age

Just across the whole thing

Just the worst thing in my

So was that your best moment just for that or for the whole thing?

Probably just this section

So do you have a best moment for all of it? So since the time you've been at hospital

Getting my transplant would have to top the

Ok I'll give you a star for that one – should I give you a star for that one?

Yeah

Because that seems pretty special. Here you go. So why would you say that tops the whole thing for you?

Because I could really just go out and be more active and have more of a social life⁵

And how were you feeling then?

At the time when I got it when I found out that I got it all I wanted to do was eat and drink and go out. As time passed, I realised there's more to that. Like I used to go to the park, I used to go to ride my bike with my brother. We used to even go running sometimes just for fun^{5 and 9}. But now we can't so you kind of realise what you *can* do and what you want to do when you got your kidney and what you need to do to look after it²¹

And what do you need to do to look after it? What do they tell you?

Drink plenty. Take your tablets²¹. I did all that but there came a point where I just didn't wanna drink anything²¹ and there came a point where I wasn't allowed to drink anything because I was admitted for having pneumonia. And due to the (masks) and all the lines and what not I couldn't²¹

Ok. So would you say, linked to what you were just talking about I guess, what's your worst moment then out of all of this along the whole thing what was your worst moment? And could you tell me a bit about it? So I've given you this one, do you want a different one?

No that's cool. I'd have to say the worst moment from each age would be. See I can't say getting relapsed cuz I do not remember that. But I'd have to say getting diagnosed with pneumonia

And when was that?

It was round about 2011 I think

Ok. And so how were you feeling then? Why have you picked that as your worst?

[Sumayah writing]

Pneumonia is hard to spell isn't it – think it begins with a 'p'. Yeah I know what you mean – I think you've got that very close actually

Do you think?

I think that's right.

I'd have to say that's the worst because had that I think 2 or 3 times and it's not the best feeling like you're not allowed to laugh¹². I was watching 'You've Been Framed' with my Dad on the ward in intensive area

where they keep you in for a really long time² and I remember watching 'You've Been Framed' with my Dad and we was laughing and then your chest feels tight and you start huffing and puffing and it's just not a nice time¹³. And you feel really you was in a confined space¹² and I was in intensive care and they don't have TV there – had to watch loads of films repeatedly. I remember watching 'Surfs Up' for the first time and loved it and then it came on on TV at home and I made everyone watch it and I was the only one that liked it

[both laughing]

Typical

Yeah

So the next thing I'm going to ask you to do is to think of a turning point. This might be a bit difficult to understand but I want you to try and have a go and if you don't want to then that's also fine

Ok

So a turning point is kind of whether you're going along your journey in life, and then something happens, that's really really really significant or something that's really important and then that changes things for you. Do you think you've had one of those? Since you've been at hospital or hospital school?

A turning point for me would be getting told that my kidney wouldn't last forever. Cuz I didn't really know that and it was quite difficult¹⁰ and no I got a few. A turning point would be being told my kidney wouldn't last forever³ and my kidneys like (needed?) blood really bad cuz it'd be a turning point then knowing that I won't have any kidneys in me and I'd be limited⁷ and. Again. So

And how were you feeling then? And how was it a turning point for you as well?

Having my kidney I was happy, glad, over the moon, had a life. But me being me I was too busy on focused on things that were either irrelevant or just not that much important²². And I went to clinic and the doctor –my consultant, Dr [name] – he told me that my kidney would not last forever² and me being me, I didn't know that^{10 and 22}, and that was a turning point because I found out that I'm gunna have to be on dialysis again. When I'm older I'm gunna need another transplant, I'm gunna have to need to be in hospital again and I didn't really want that. Another the other turning point when my kidney was bleeding it wasn't at first it was a little bit of blood wasn't that bad then my urine was 90% blood and then they said to me² that I'm gunna need to get my kidney taken out or have blood transfusions every week. And I just got really upset knowing that I won't have no kidneys and I have to drink a little bit¹⁰. Yeah. So that was my they are my turning points

I think you did really well at explaining that actually and I think, it sounds to me as well like if it was a turning point because you thought things were going to be one way and then something happens and then you're like oh this is the reality of how it's gunna be. Is that right?

Yeah that's what it is. It's pretty much *that*.

Yeah it's because you've done a brilliant job at explaining. Now I'm gunna ask about 2 or 3 people that you've found significant so these are people you know we said this is a bit like a book, so these are 2 or 3 characters who have had a really important impact on your life. So they don't have to be important people but important

My hospital life?

Yeah your hospital life and hospital school life as well if you can think about that as well

[name] would be the first one

You can have one of these or you can just tell me about it if you like

I'd rather tell you. [name] has always been in my life from the start of dialysis she's still here she's been taking care of me from the start²³. She even used to take care of my *Mom* and she used to take care of my siblings

Really?

Yeah. The second one would be Dr [name]. Very close to him he's been my consultant from the start²³

Since you were like 1?

Yeah Then it would be Farah. Like she's helped me through a lot. Like we've been close and been together really¹⁷

APPENDIX SIXTEEN: FURTHER EXPLANATION OF THE HOLISTIC STAGE OF DATA ANALYSIS

Gergen and Gergen's (1984) typology:

I utilised Gergen and Gergen's (1984) typology in the holistic phase of data analysis in order to analyse each narrative according to their temporal structure. This was to explore how CYPCCs viewed their experiences of hospitalisation and hospital school in relation to time and context and the development of their evaluations over time. Gergen and Gergen (1984) categorises narrative forms as progressive, stable or regressive.

In progressive narratives, the protagonist undergoes a transformation that is resolved in coherence and integration. The calculation of self across the events of the narrative results in a new understanding or a new way of relating, for example as is typical in a 'coming of age' story. Progressive narratives often involve a process of self-reflection and identity quests.

Stable narratives are characterised by little or no transformation over time. The events of the story are related as 'happenings' that have no lasting effect on characters (Lightfoot, 2004). Gergen and Gergen (1984, p. 175) indicate that in stability narratives the protagonist "remains essentially unchanged with respect to evaluative position", although this can be at any point along the evaluative continuum i.e. consistently negative or positive evaluations.

In regressive narratives, the change over time is marked by increasing disintegration and incoherence. Lightfoot (2004, p. 28) suggests that the "character in these stories are undone; they unravel in the face of what is usually overwhelming adversity". The impact of these significant life events can lead to negative emotions and happenings such as unrequited love, suicide and emotional limbo.

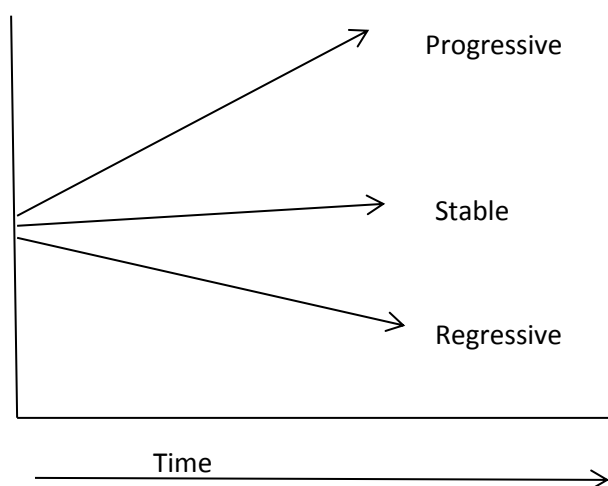


Figure AF1: The temporal structure of stories (taken from Lightfoot, 2004 p. 27)

The use of genre:

During the holistic phase of data analysis, I explored each narrative according to its 'genre'. The use of 'genre' as an analytic tool was considered important as a way of exploring the form of the narratives, which was of interest to me as researcher. Moreover, genres can bring the heart of the story to the fore. Furthermore, as it provides a culturally shared framework, genre can be used to structure experiences in a meaningful and easily communicable way (Elliott, 2005). It was also anticipated that genres would facilitate theorising processes. Furthermore, methodological literature suggests that the kind of story an individual

tells about a period in their life can have a significant impact on that person's well-being (Gergen, 2004). Squire et al. (2014) however, argue that the application of genre categories to narratives can be overly simplistic and can ignore particular socio-political contexts, as well as the specificities of personal narratives. To this end, I have attempted to overcome this limitation by not *only* conducting holistic analysis for each narrative as the sole means of analysis, but I also conducted three other analytic phases for each narrative, i.e. narrative summaries, re-storying and thematic analysis.

Two different types of genre category were used for the present study, namely literary genre (Czarniawska, 2004; Lieblich et al., 1998) and illness narratives (Frank, 1995). Although ill-health is not the focus of the research per se, it is relevant as this is what brought the CYPCCs to hospital and is a mutual experience shared by all participants, though these are likely to be diverse. I considered the framework useful as a way to recognise and understand the impact of ill-health on the construction of their experiences. Tables A3 and A4 outline the different types of literary and illness narrative genres respectively.

A3: Summary of literary genres as defined by Czarniawska, 2004, p. 21

Literary genre	Description
<i>Romance</i>	The standard plot of a romance is one in which the protagonist, after experiencing a number of adventures and trials, regains what is lost –love, the meaning of life, success and glory or all of the aforementioned. The hero is symbolic of order and their enemies represent the forces of evil etc. The assumption underpinning romance is that all creatures in the world have a true and deep meaning which the hero can reveal.
<i>Tragedy</i>	Tragedy views humankind as subjected to a number of laws of fate, laid bare through the central crises apparent throughout most of the narrative. Gergen and Gergen (1984) refer to the tragic narrative as being representative of a rapid downfall.
<i>Comedy</i>	In the comedy genre, despite setbacks and complications, everything resolves into harmony – the characteristic ‘happy ending’.

A4: Summary of illness narratives based on Frank (1995)

Illness narrative	Description
<i>Restitution</i>	In the restitution narrative, illness is seen as temporary or transitory. This narrative focuses on the returning of the body to its former self, prior to illness.
<i>Quest</i>	Quest narratives accept illness and suffering and seek to use it. Illness is regarded as a journey which becomes a quest. In this type of narrative, the opportunity to grow, learn and become wiser is the focus, for example with regard to closer relationships, more poignant appreciations and clarified values.
<i>Chaos</i>	The chaos narrative in a sense is the ‘opposite’ to the restitution narrative because it does not indicate that life will get better and the person is without hope. Frank (1995) refers to this as the ‘anti-narrative’ as these narratives are often characterised by lack of sequence and incoherence. This is often the case when individuals are overwhelmed by their illness experiences.

APPENDIX SEVENTEEN: DEVELOPMENT OF CODES AND THEMES

During the thematic analysis aspect of the data analysis process, codes and themes were developed in relation to the narrative of each participant. This appendix outlines the development of codes and themes in relation to two participants, Suzan and Farah, used as exemplars for the process of developing codes and themes.

Thematic analysis for Participant 1 - Suzan:

Codes:

Table A5: Development of codes identified in Suzan's narrative

Code name	Quotation
1. Change of hospital	<p>"going to other hospital soon"</p> <p>"I feel kind of sad I'm leaving them [nurses]"</p> <p>"Because I will be missing the nurse and other children" (in response to question re: her sadness at leaving hospital)</p> <p>"been in to see the hospital but I don't like it"</p> <p>"I know it's nice but I don't like the hospital, it's scary"</p>
2. Kidneys	"my kidneys is not working well"
3. Scared	<p>"was scary for me" – when first came to hospital</p> <p>"I first come in I was a bit scary"</p> <p>"I know it's nice but I don't like the [new] hospital, it's scary."</p>
4. Restriction to participation in school	<p>"I couldn't go to school"</p> <p>"but I couldn't go because I was on dialysis"</p> <p>"And there were some lines in my neck so I couldn't go <i>out</i> to school so I didn't been"</p>
5. Ill-health	"I was really sick really really sick"
6. Medical staff helping	"If they wouldn't changing my blood I would be losing my life. Straight away they straight away when I come here they change my blood"
7. Nurses helping and relationship with nurses	<p>"nurses take me to the school so I was learning English too"</p> <p>"I was having fun with the nurses in 2015"</p> <p>"They were helping so much. They were working so hard to make me feel well"</p> <p>"I feel <i>really</i> great that they were so kind to me"</p> <p>"they're great"</p> <p>"I been knowing them since four years. Long time"</p> <p>"They always been really nice and () when I need something they always do for me"</p> <p>"I was learning so many stuff from those nurses"</p> <p>"Because I will be missing the nurse and other children" (in response to question re: her sadness at leaving hospital)</p>
8. Hospital school teachers helping	<p>"Before I done my science exam [name] used to come, my Maths teacher did teaching me. [name] was teaching me as well – English"</p> <p>"teachers were helping me they was"</p> <p>"Yeah they was really working hard to teach me and to get good grade"</p> <p>"They teaching me like the science teacher teaching me all the three things chemistry biology physic and they teach me the ecology all the"</p> <p>"I know when I was going to college if I didn't went here it would be hard for me cuz they was all working hard for me with my work ()"</p> <p>"teachers has helped me"</p>

Code name	Quotation
	<p>"They was teaching me very really hard"</p> <p>"I was been learning by them. The English teacher first when I come back he was teaching me so I was learning really well with him. So I think the teachers really good"</p>
9. Pain	<p>"When I first come in ... and was really painful... when they basically take the blood out from my neck"</p> <p>"And all blood take some line out of my neck is painful"</p> <p>"I wasn't feeling good because it was painful each time when they change it and putting another one in the side"</p> <p>"I wasn't couldn't moving my because of the pain"</p> <p>"My family was kind of sad because I was really painful"</p>
10. Restriction to daily living	<p>"I couldn't even take a shower"</p> <p>"I wasn't couldn't moving my because of the pain"</p> <p>"I couldn't eat and think when the line was in my () .I couldn't. That was horrible time"</p>
11. Dad's absence/presence	<p>"Well that time my dad wasn't here so"</p> <p>"I was my dad was come"</p> <p>"They [parents] was coming and visit me"</p>
12. Mum's commitments	<p>"But my mum was [here]. My mum was a bit busy. So she was have to go pick up my sister and brother and come back so that time wasn't very nice"</p> <p>"My mum could come with me and go home. I was a bit better"</p> <p>"When I was here when I was in operation so I was missing my mum because my mum couldn't come here"</p> <p>"they [parents] was coming and visit me"</p>
13. Speaking English	<p>"I couldn't speak any English... I couldn't. I didn't know any English at all" (when she first went to school)</p> <p>"Nurses take me to the school so I was learning English too"</p> <p>"Yeah in hospital school that was a good I was learning some new words"</p>
14. Other children	<p>"() like was other students other children were sitting on table and they was pieces of paper was have to write down"</p> <p>"Because I will be missing the nurse and other children" (in response to question re: her sadness at leaving hospital)</p> <p>"I see them [other children] when I used to before coming on Monday. Monday, Wednesday and Friday so I seen them"</p> <p>"they are my friends"</p> <p>"I love the little children they are nice... [name of small child]"</p>
15. Older brother	<p>"My older brother was with me"</p>
16. Learning/ personal growth	<p>"So I feel like I grown with them [nurses]"</p> <p>"I was been learning by them [teachers]"</p> <p>"I feel is getting good because at the first I couldn't even write"</p> <p>"Couldn't write or read. Or spell my name. I didn't know anything at first really. I didn't even know to go on a (park) on myself."</p> <p>"And now I could go shopping by myself. I can everything by myself"</p> <p>"Like I grow. I learn each style what to do"</p> <p>"Was so tiny when I come here I duno. I don't remember... When I was 11 I was so tiny...Yeah. Like small small"</p>
17. Uncertainty	<p>" I dunno if I will still on dialysis or no"</p>
18. Determination/ working hard	<p>"I think it's not, if I try to ... hard then it'll be ok"</p>
19. Reflection on the past	<p>"It was nice to I make make me to remember the past of myself. I was forgetting of them but now I will think about it I'll remember them"</p>

Code name	Quotation
20. Boredom	<p>"I get bored sometimes because there's nothing to do sometimes"</p> <p>"In one hour I try like 50 different things to do sometimes when I am getting bored"</p> <p>"I do (d-), playing my phone, listen to song, playing jigsaw puzzle, watching TV, changing movies"</p> <p>"In TV watching movies on the iPad was getting bored really sometimes but if there was not antennae sometimes I will getting bored really"</p> <p>"because I got internet I was watching character Disney so I was not bored"</p> <p>"today the internet's rubbish it's not working so I'm bored"</p>

Themes:

Table A6: Development of themes identified in Suzan's narrative

Themes	Codes
Help from hospital staff	6, 7 and 8
Restriction	4 and 10
Ill-health and pain	2, 5 and 9
Family presence	11, 12 and 15
Change, growth and personal development	13, 16, 18 and 19
Other hospitalised CYPCCs	14
Uncertainty about future	1, 3 and 17
Boredom	20

Additional comments in relation to the development of themes:

- Related and/or overlapping codes were grouped together into themes
- Some original themes were removed, for example 'pain' which was incorporated into a new theme entitled 'ill-health and pain'. An original theme called 'fear' was also removed as a theme and included into the theme concerning 'uncertainty about future'.
- Some themes were renamed, for example an original theme named 'other children' was more accurately renamed to 'other hospitalised CYPCCs'. This was judged a more accurate description as Suzan did not speak of other children generally e.g. at home school or family members, but rather spoke specifically about hospitalised CYPCCs. A theme entitled 'uncertainty' was also renamed to 'uncertainty about future' for accuracy purposes once more.
- Some codes were considered important to the extent that they were identified as themes in themselves, namely 'boredom' and 'other hospitalised CYPCCs'.

Thematic analysis for Participant 2 - Farah:

Codes:

A7: Development of codes identified in Farah's narrative

Code name	Quotation
1. Leaving presents	<p>"I'm gunna give it [pen] to someone"</p> <p>"Yeah I give I gave everyone [presents]"</p> <p>"This is for you. And you're allowed these sweets. You can have them in a bit. I'll put them in a plate for you, alright." (to another CYP)</p>
2. Routineness/ mundaneness of	<p>"Feels like the same all the time on here"</p> <p>"All the nurses, doctors, everyone"</p>

Code name	Quotation
hospital	
3. Hospital teaching	<p>"I never really went to school or nothing. It's only now this year that they've been teaching me"</p> <p>"I can't really remember before. I never used to go to their school"</p> <p>"When I be admitted then they used to teach me like sometimes"</p>
4. Leaving children's hospital/ starting adult hospital	<p>"Scared... Because it's something all new and new faces. It's bigger and I been here since I was 3."</p> <p>"In <i>there</i>, it's different all the nurses cuz it's bigger and everything"</p> <p>"And me and Suzan are moving together now so it's more easier for (us/her)"</p> <p>"Feel upset. But I don't think it's proper hit me yet."</p>
5. Not celebrating	<p>"It's not a party it's like... They just getting food. Not gunna celebrate"</p> <p>"It's not a party it's just"</p>
6. Pain	<p>"It [pancreatitis] was pain... Really bad. A lot of pain"</p> <p>"I went to intensive care for 3 days with it and I was on loads of morphine"</p>
7. Support from nurses	<p>"All the nurses... Cuz they been looking after me. Since I was small"</p> <p>"Looked after me. Like gave me my correct medicines and got me better"</p>
8. Emotional support	<p>"Like when I'm ill and just fed up. Just like convince me and make me happy." [Playworkers]</p> <p>"Talk" (when talking about what she does with Playworkers)</p> <p>"It's been hard. But at the same time I've got through it with all the help"</p> <p>"All this treatment. It's hard. But you have to deal with it. And everyone's really supportive so"</p>
9. Knowing everyone/making friends	<p>"And I know everyone here, all the kids, all the nurses, everyone. And everyone here like it's like you see them, everyone, all the time."</p> <p>"Getting to know everyone. Like <i>properly</i> on dialysis and making friends."</p> <p>"But I used to see them around like [name of boy] and Suzan. I never really got to know them. But now I got to know them"</p> <p>"Always see [name of boy] in [name of entertainment plaza] and everything"</p> <p>"It's <i>nice</i>. Like a big family"</p>
10. Activities in hospital	<p>"Because they take me out wherever I want and they help me out in the good and the bad times... Town... Yeah. Took me loads. [Name of Playworker 1] takes us to workshops because she does transition for the adult hospital."</p> <p>"Yeah they like on dialysis, [name of Playworker 1] like she does like activities with us, sometimes we do like a mystery box, we have to put our hand in there and we have to guess what it is and whoever's got the most ten things whoever's got the most right gets a prize at the end... They put hair gel and everything"</p> <p>"Talk. Arts and crafts. Anything"</p>
11. Doctors/ medical treatment	<p>"There are loads of doctors"</p> <p>"My doctor"</p> <p>"Because they gave me the right treatment when needed and. They been looking after me since I was small."</p> <p>"They're the ones in charge"</p> <p>"Sometimes they used to stress me out. Like more and more medicine but they just do it for the right reason so"</p>
12. Energy	<p>"When I had the transplant I was I had more energy. I had more energy"</p>
13. Physical	<p>"I grew."</p>

Code name	Quotation
Appearance/ normality/ body image	" My hair got better my skin, everything was just like normal"
14. Restriction to food and drink	"Cuz I'm on a fluid restriction and I'm only allowed 500mls a day and we're limited with what we can eat, low phosphate and potassium."
15. Liberation	"You can drink and eat whatever you want" "And when you have a kidney you can have anything" "[Anything?] Yeah anything. Yeah" "No more lots of hospital no more dialysis"
16. Close/strong relationships	"I knew Sumayah all along. Me and her were like <i>tight</i> . Because we used to stay on the ward and everything together. Like before." "One big family"
17. Getting used to things/becoming accustomed	"I'm hoping to get a kidney, settle down in the [name of (new) hospital]" "Like getting used to it, like knowing the place. I dunno about the nurses and that cuz it's all different all the time there because it's huge"
18. Uncertainty	"I'm <i>hoping</i> I get a kidney" "Driving. I dunno what else. Working [And then would you be a hairdresser?] Hoping"
19. Family	"One big family" "My Mom... She helped me. And my Nan. All the time... Coming in. Getting me what I want and everything"

Themes:

A8: Development of themes identified in Farah's narrative

Themes	Codes
Anticipation about transferring hospitals	4 and 5
Activities in hospital	3 and 10
Support/ relationships in hospital	1, 7, 8, 9, 16 and 19
Benefits of kidney transplant and challenges without	12, 13, 14 and 15
Uncertainty about the future	18
Routine	2 and 17
Medical intervention/treatment	6 and 11

Additional comments in relation to the development of themes:

- Some codes were collated to establish one theme, for example 'support/relationships in hospital' which, after combining several codes, includes support PWs, nurses and other hospitalised CYPCCs
- The theme 'uncertainty' was renamed to 'uncertainty about future'. Moreover, the theme 'anticipation re: leaving children's hospital and starting at new (adult) hospital' was renamed to 'anticipation about transferring hospital'.

APPENDIX EIGHTEEN: COMMENTS RELATING TO SAJID'S MOTHER'S 'PARENT NARRATIVE'

During the course of Sajid's interview, Sajid's mother made numerous comments relating to her own personal narrative and experience, rather than directly contributing to Sajid's narrative. Although interesting and thought-provoking, these were considered irrelevant to the RQs and research focus and therefore inappropriate for analysis and interpretation. It is to be noted however that comments made by Sajid's mother contributing to and supporting with Sajid's narrative have been included in the analysis of his narrative. Table A9 outlines comments in relation to Sajid's mother's 'parent narrative' relating to her own experiences as a mother of a CYPCC.

Table A9: Quotations from Sajid's mother in relation to her own experiences as a mother of a CYPCC ('parent narrative')

Quotation	'Parent narrative'
<p>"You're going to have a special medicine, that's what I used to say to him you're going to have a special medicine"</p> <p>"That's how we introduced it to him today's the day to have your special medicine"</p>	Introducing the treatment/medical intervention to child
<p>"It's accepting it wasn't it and you know when you have this first child and you have loads of hopes and me working in a school always... You see children and you work with special needs and one day it all turns back to you it's quite hard to accept"</p> <p>"I think if you haven't seen that side, for another mom, it would(n't) be that hard to accept. Me it was quite hard to accept I always thought"</p> <p>"He's not able to be at the top in everywhere like his speech, his communication... Wasn't great and I didn't pick up on that for many months you don't realise things"</p> <p>"It's quite hard it doesn't matter I was working in a school environment because I'm a nursery nurse myself but when it came to my own child I felt a bit delayed to identify things or maybe it was harder for me to accept to take it all in Wanting to do the best for their son and when he had the diagnose and things weren't good you know I sort of accepted I get it."</p> <p>"what your thoughts, what you expect or want from life... and how it all changes you accept it"</p> <p>"still remember when they first diagnosed him... and if I hadn't worked in a school with children then maybe () just killed me"</p>	Acceptance of child's condition – coming to terms
<p>"() if he's not bright doesn't matter if he doesn't talk so much doesn't matter if he's not able to tell you, as long as he's healthy. (That's everything) to me."</p> <p>"He's not climbing up that frame, it's ok."</p> <p>"If he's not riding that bike or running, it's ok but it did take me a long time to accept all that"</p>	Putting things into perspective/ shifting expectations/priority changing

Quotation	'Parent narrative'
<p>"Now I think this probably sounds wrong having him in front of us and being well is the most important thing"</p>	
<p>"Like we've got a 4 year old and that 4 year old now always () my daughter was is not like him as well. He went to nursery when he was 2, he does whole days, he's so active and like you see this picture you get up in the morning go to school and nursery, normal routine but with Sajid we never had that with him. With [name of other son] even if he's tired or he's had a long day he's off like a rocket in the morning, he's full-time"</p> <p>"() his speech. When I look through his book bag I say () the big words he comes out with you know 'deliberately' and 'purposely' like those big words that he has"</p> <p>"He talks he just talks at the age of four it's just shocking for you to see those big words and his independence like dressing himself, and everything – he wants to do it and that independence we didn't see that sort of"</p> <p>"I think going to nursery from a very young age does make a lot of difference ... because of his health he [Sajid] didn't get to nursery til he was 4 and when he did he was never well to go () be there with () he only used to do afternoons and he couldn't even manage that. Like with [name of other son] does 9 til half past 3 9 til... Yeah and he even has school lunch there as well and physically as well he's always on the bike he's go go go. We never saw"</p> <p>"If you're happy in yourself and you've got a lively childhood you <i>wanna</i> do more things but if you are unwell yourself I think the enthusiasm isn't there Is it"</p>	<p>Comparison of Sajid's development to that of her other (younger) children.</p>
<p>"I never put him behind if he wants to do something () so we took him to bike lessons. Even though he can't do it all the time and he can't do it often to be able to say I can do it"</p> <p>"He doesn't like to be (t-) took him to the leisure centre when they were doing bike lessons several times we went but he didn't wanna have the lesson with the younger children which we thought would be better but then we had to give him 1 to 1 done that we've given him tuition at home privately as well to boost his ()"</p>	<p>Encouraging her son</p>
<p>"I think health wise it was too much for him we wanted to take him home and () physically he wasn't well enough to move picking him up so we put him in a wheelchair and picking him up and making him tired... : we didn't know if it was the right thing to do... getting him out of here and he's not well enough"</p>	<p>Unsure if she's doing the 'right thing'</p>

Quotation	'Parent narrative'
<p>"I'm doing my nursing through my son... you learn more from experience... I think experience you learn quicker you pick up a lot don't you "</p>	<p>Learning journey as a parent</p>
<p>"I think it's the bond as well that you build with people in hospital they all () but you build a bond and you feel they're your family... that's how I see it. Like the nurses we were so close to the nurses at [name of another hospital] 5 months being with them all the time"</p> <p>"Play specialists, consultants, even though you have your friends and your family, these are your friends and family in here"</p>	<p>The hospital community as support for herself and her family</p>
<p>After the audio recorder was switched off, Sajid's mother spoke to me about the important role of Islam in supporting her own journey with her son. At the time of the interview it was Ramadan and so she spoke of her fasting and her relationship with God. Sajid's mother said that when Sajid is better she wants to take him to "God's house", where miracles happen. She is hoping for a miracle to happen for Sajid.</p>	<p>The role of religion/ faith</p>

APPENDIX NINETEEN: DATA ANALYSIS: INTERPRETATIONS OF NARRATIVES OF SUZAN, FARAH, ROSE AND SAJID

SUZAN

Suzan's interview took place in the afternoon on a busy and noisy ward with many other CYPs and adults present. Suzan sat on a chair, as did I, next to her bed. The curtain was pulled for additional privacy, which Suzan preferred. Suzan was connected to a dialysis machine for the duration of the interview. Analysing Suzan's data was challenging at times due to Suzan having English as an additional language, which meant that her English expression and accent were at times difficult to decipher. Furthermore, Suzan's voice was quiet, and often became obscured by the frequent and loud background noise of the ward. At times, I found it challenging to listen to particularly intensely painful experiences in Suzan's narrative. I reflected that this left me feeling helpless and in a low mood.

Holistic Analysis

Table A10: Holistic analysis in relation to Suzan's narrative

	Classification	Researcher Interpretation
Progression of plot (Gergen & Gergen, 1984)	Progressive	In terms of narrative structure and development, Suzan's story appears to be progressive. This is because despite challenges with her health and much physical pain and difficulties endured, Suzan emphasises the role of progression, change and growth throughout her narrative. Her narrative account appears to be one of appreciation and gratitude for the extent of her development, in several areas such as academic competence and her health, compared to when she first arrived at hospital. Suzan is thankful for the contributions and support of others in her development, particularly nurses and hospital school teachers, with whom she has developed positive relationships. Despite some anxieties about entering into adult care and thus the transference of her care to an adult hospital, she appears generally optimistic about the future.
Genre of narrative: 1. Literary (Lieblich et al., 1998; Czarniawska, 2004) 2. Illness narrative (Frank, 1995)	1. Romance 2. Quest narrative	In terms of genre of the narrative, I deem Suzan's narrative to fit into a romance genre. This is because although the protagonist (Suzan) endures many challenges and trials, including one which was life-threatening, she overcame these obstacles and battled valiantly. As a result of these difficulties, Suzan grew and changed as a person. I interpret that she emerges victorious, with a renewed sense of self fulfilment. I also interpret Suzan's narrative to fit a quest illness narrative due to the focus of Suzan's narrative on the acquisition of knowledge, understanding and skills, and the fact that as a result of her experience of hospital and HS, she has become a different, newer and wiser self.

Suzan's experience of hospital and HS can be characterised by progression, development and change as a result of events and experiences which have challenged her physically and emotionally and which she has overcome.

Narrative Summary

Table A11: Narrative summary of Suzan's experiences of hospital and hospital school

	Interpretation
<i>Beginning</i>	When Suzan first came to hospital at around 10 or 11 years old, this was a fearful time for her. She described that she was particularly ill at this time and only survived due to a life-saving occurrence in which medical staff at the hospital 'changed her blood'. She described intense pain when she had a dialysis line inserted into her neck. At this time, she did not attend school due to her severe ill-health. Her Dad was not in the country at the time and she describes things being difficult for the family as her Mum could not always be there in hospital with Suzan, due to commitments pertaining to her younger siblings.
<i>Middle</i>	Suzan first went to school at aged 13 and did not speak any English. She also attended hospital school at this time and learned some English there. Her Dad came to the UK, which made things slightly easier for the family. Suzan had many operations in one year (approximately aged 13 years), which she described as very difficult and painful for her and her family.
<i>End</i>	Suzan described 2015 to be her best time because teachers at the HS supported her and worked hard to help her with her GCSE exams. She also expressed happiness and gratitude as a result of the support she received from nurses and the fun times she had with them. At the same time however, Suzan was clearly apprehensive about her future as she was due to move into adult care in the next week. She expressed fear about moving hospitals (from the children's hospital to an adult hospital) in addition to expressing sadness that she would miss the children's hospital and the people in it as a result of moving.

Narrative Restorying

Table A12 below outlines the interpretative process of restorying Suzan's narrative. The chapters she identified herself have been utilised to frame the key events and experiences which occur during each time-frame. Exemplary quotations relating to Suzan's evaluations of these events and experiences are included, in addition to my own interpretative comments.

Table A12: Suzan's event and experience-centred narrative with additional researcher interpretation and commentary

"The Life of the Little Girl that Changed" ¹			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative Comments
Chapter 1: 10 or 11 years	Suzan first came to hospital	<ul style="list-style-type: none"> • "I was really sick really really sick." • "If they wouldn't changing my blood I would be losing my life" • "I was a bit scary and was really painful" • "That time my dad wasn't here so. But my mum was. My mum was a bit busy. So she was have to go pick up my sister and brother and come back so that time wasn't very nice" 	<p>Suzan describes how she found hospital when she was first admitted, largely in terms of <u>physical pain</u> ("really painful") and <u>fear</u> ("I was a bit scary", "scary for me"), which she repeatedly emphasises. Suzan explains how the removal of blood from her neck was particularly painful. The fear Suzan depicts may be as a result of the new environment, the fear for her life, the anticipation of pain or her inability to speak or understand English at the time.</p> <p>Suzan describes how she was <u>very ill</u> when she first arrived at the children's hospital and how medical staff saved her life, somewhat with a sense of urgency ("straight away they straight away when I come here they change my blood"), which perhaps indicates that she views their urgency as indicative of commitment to making her better.</p> <p>Suzan also describes <u>difficult family circumstances</u>, in which her father was not yet in the UK and her Mum therefore found it difficult to juggle looking after Suzan's two younger siblings as well as being in hospital for Suzan.</p>
	Suzan was not in school	<ul style="list-style-type: none"> • "I couldn't go to school" • "My brother since 4 but I couldn't go because I was on dialysis" • "There were some lines in my neck so I couldn't go out to school " 	<p>Suzan often uses the word "<u>couldn't</u>" when referring to her non-attendance at school. This might indicate that Suzan would have liked to attend school, but due to her health, this <u>impeded/restricted her desired participation</u>. Suzan also compares her lack of attendance at school with her younger brother, who was able to attend school, from a very young age.</p>
Chapter 2: 12 – 15 years	Suzan's Dad came to the UK	<ul style="list-style-type: none"> • "So my mum could come with me and go home. I was a bit better when I 	<p>The <u>change in family circumstance</u>, with Suzan's father arriving to join his family in the UK, was positive for Suzan. His arrival meant that her Mum was able to spend more time in hospital with Suzan, which possibly impacted on</p>

¹ This title was given by Suzan. This was in response to my interview question towards the end of the interview, inviting her to reflect on her story and to think of a title for it. This relates to the story being akin to a book or a film.

“The Life of the Little Girl that Changed” ¹			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative Comments
		was 13 year old 14”	her emotional wellbeing (“I was a bit better”).
	Suzan went to school when she was 13 years old	<ul style="list-style-type: none"> “I couldn’t speak any English... I didn’t know any English at all” 	The fact that Suzan was <u>not able to speak any English</u> when she started school appears significant to her.
	Suzan attended HS when she was admitted to hospital for an operation	<ul style="list-style-type: none"> “So I was missing my mum because my mum couldn’t come here so the nurses take me to the school” “So I was learning English too... Yeah in hospital school that was a good I was learning some new words” 	It appears that for Suzan, having her <u>Mum in hospital</u> when she is having medical intervention, such as an operation, is important. When her Mum was not present, Suzan missed her. There appears to be a connection between Suzan’s mother’s absence and her attendance at the hospital school (“because my mum couldn’t come here so the nurses take me to the school”). Therefore, her Mum’s absence led to the nurses possibly wanting to distract Suzan or take her mind off missing her Mum by taking her to the hospital school. Suzan described that she learned some English in HS, which she viewed as being positive in supplementing her learning at her home school. Furthermore, Suzan’s HS experience also involved social interaction with other hospitalised peers.
	At approximately 11 – 13 years Suzan had four or five operations in one year (*worst moment*)	<ul style="list-style-type: none"> “I wasn’t feeling good because it was painful each time when they change it and putting another one in the side. I wasn’t couldn’t moving my because of the pain” 	Suzan described a particularly awful time for her, when she had <u>four or five operations</u> in a short space of time (one year). Suzan described this occurrence as being the worst moment out of all of her time in hospital and HS. Suzan describes the experience in terms of the physical pain she endured and the restrictions to her movement as a result of this pain.
Chapter 3: The present - aged 16 years	Preparation for GCSE exams	<ul style="list-style-type: none"> “Teachers were helping me they was... Yeah they was really working hard to teach me and to get good grade” 	Suzan recognised <u>HS teachers’ efforts</u> in helping her to prepare for her GCSE exams and to help her to achieve optimal grades. Despite Suzan not particularly enjoying Science subjects, specifically Physics, Suzan appeared to appreciate the teaching from the HS teachers and inferred that without this help, she would find it more difficult when she starts college soon. In this respect, the HS teachers have made a difference to Suzan’s future educational experiences. Suzan’s use of ‘for me’ in the phrase “they was all working hard for me with my work” may infer that she perceives HS teachers’ efforts to be

“The Life of the Little Girl that Changed” ¹			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative Comments
			over and above their duties.
	Suzan enjoyed the company of the nurses (*best moment*)	<ul style="list-style-type: none"> “I was having fun with the nurses in 2015” “They were working so hard to make me feel well” “I feel really great that they were so kind to me” 	Suzan spoke enthusiastically about her experience with the nurses and expressed that she had <u>fun with them</u> . Suzan expressed <u>happiness and gratitude</u> that the nurses helped her so much and worked hard to help her to be healthy. Suzan chose 2015 with the nurses as her best moment, which demonstrates her positive relationship with them, as well as the impact the nurses and her relationship with them has had on her (see future chapters).
Future chapters	Suzan is healthy and working as a nurse (long-term future)	<ul style="list-style-type: none"> “The future life I was well and I was doing my work as a nurse. That’ll be great” 	Suzan first commented on her <u>health</u> when referring to her future, which suggests that this is understandably her priority for the future. Suzan expressed that she wants to be a <u>nurse</u> in the future, perhaps representative of the <u>impact her experience with nurses</u> has had on her. Suzan stated that she had learnt a lot from the nurses, which has contributed to her future career aspiration.
	Studying (short-term future)	<ul style="list-style-type: none"> “At [name of college], at home, doing a course and coming home. I imagine that will be hard and I duno if I will still on dialysis or no...” 	Suzan explained that in the short-term (one year) she wants to be <u>studying</u> and doing a <u>college course</u> , which she anticipates will be difficult. She expressed uncertainty about whether or not she will continue to be on dialysis, although she would prefer not to be on dialysis in one year’s time. Generally, Suzan appeared optimistic about the future as although she feels college is likely to be difficult, she expressed that if she tries hard “then it’ll be ok”. I interpret this to indicate that Suzan feels that with regard to her future, <u>the locus of control is somewhat internal</u> .
	Living abroad	<ul style="list-style-type: none"> “Going in different country. I like to be go to Korea” 	Suzan expressed that she would like to live abroad in South Korea. I interpret this aspiration as a positive reflection of Suzan’s perceptions of her own capabilities in light of her CC and the fact that she feels that her <u>condition will not inhibit her from travelling or living abroad</u> .

Themes

Using a thematic approach to analysing data from Suzan's original transcript, 8 themes were identified in relation to her narrative, as represented in Table A13. Codes were initially identified based on Suzan's original transcript (see Appendix 17 for complete list of codes and quotations). These codes were then grouped into themes (Appendix 17). Table A13 details each theme with exemplary quotations which support the identification of each theme.

Table A13: Thematic Analysis - Key themes interpreted from Suzan's narrative

Themes	Exemplary Quotations	Interpretation
1. Change, growth and personal development	<p>"I didn't know any English at all"</p> <p>"Couldn't write or read. Or spell my name. I didn't know anything at first really. I didn't even know to go on a (park) on myself."</p> <p>"I feel like I grown with them [nurses]"</p>	A predominant theme from Suzan's narrative is her journey of change, growth and personal development. Suzan explained that when she first came to hospital, she was unable to speak English and this is something she has learned over time. She has also learned academic skills e.g. reading, writing and spelling her name as well life skills, namely independence. Suzan demonstrated a sense of determination as part of her development and expressed that if she works hard challenges such as college, are surmountable.
2. Help from hospital staff	<p>"If they wouldn't changing my blood I would be losing my life"</p> <p>"They were helping so much. They were working so hard to make me feel well"</p> <p>"They always been really nice and () when I need something they always do for me"</p> <p>"Yeah they was really working hard to teach me and to get good grade"</p>	Suzan spoke about hospital staff positively and indicated her appreciation for this support. Suzan spoke about her first arrival at hospital and how medical staff immediately intervened to save her life. Suzan identified nurses as 'key characters' and significant to her hospital experience. Suzan has developed positive relationships with the nurses and has enjoyed having fun with them and has known them for a long time (4 years). Suzan indicated that she had learned a lot from the nurses, and I interpret this as being influential in her aspiration to become a nurse. Suzan spoke about HS teachers appreciatively due to their efforts in preparing Suzan for her GCSE exams. The HS's role in Suzan's development and learning is also significant, and she mentioned at one point that it was her only means of formal education.
3. Ill-health and pain	<p>"My family was kind of sad because I was really painful"</p> <p>"I was really sick"</p>	Another theme that emerges strongly from Suzan's narrative is the significant pain and sickness she has endured as a result of her medical condition. Suzan notes that this is not only difficult for her, but her family too.
4. Restriction	<p>"I couldn't go out to school so I didn't been"</p> <p>"I couldn't even take a shower"</p>	Linked to theme 3, I interpret restriction to be another theme in Suzan's narrative. Suzan notes that as a result of her significant ill-health she has been limited regarding

Themes	Exemplary Quotations	Interpretation
	"I couldn't eat and think... That was horrible time"	participation in school and also in terms of daily living. Suzan identified that when she is in extreme pain she can be constrained regarding her movement and simple tasks such as showering and eating.
5. Family presence	"But my mum was [here]. My mum was a bit busy. So she was have to go pick up my sister and brother and come back so that time wasn't very nice" "My mum could come with me and go home. I was a bit better" "I was missing my mum because my mum couldn't come here"	I interpret a predominant theme in Suzan's narrative to be the presence of her family. When her father was not living in the UK, this was difficult for her family and meant that her mother had to balance several commitments. I interpret that Suzan values her family being physically with her in hospital and misses them when they are absent. Although Suzan did not mention her family when asked about significant people during her experience of hospital and HS, I judge from her narrative, that they are an important part of her experience.
6. Other hospitalised CYPCCs	"I will be missing the nurse and other children" "they are my friends" "I love the little children, they are nice... [name of small child]"	Suzan has developed positive relationships with other hospitalised CYPCCs and considers them to be friends. Suzan also conveys a fondness for the younger children. Suzan expressed that she would miss the other children when she transfers hospital.
7. Uncertainty about future	"Been in to see the hospital but I don't like it" "I know it's nice but I don't like the [new] hospital, it's scary" "I dunno if I will still on dialysis or no"	Suzan expressed early in the interview that she would soon be transferring hospitals, about which she felt apprehensive. Although she visited the hospital and acknowledged that it was nice, she still considered it to be scary. Suzan expressed further uncertainty about her future, stating that she does not know if she will still be on dialysis.
8. Boredom	"In one hour I try like 50 different things to do sometimes when I am getting bored" "I do (d-), playing my phone, listen to song, playing jigsaw puzzle, watching TV, changing movies"	Suzan expressed that boredom is integral to her hospital experience. Suzan expressed that she actively attempts to entertain herself, largely through technology such as TV, watching movies on her iPad and playing games and music on her phone. Suzan expressed that when the internet is not functioning, this increases her boredom.

FARAH

Farah's interview took place in the afternoon on a busy ward with many other CYPs and adults present. Farah lay in her bed connected to a dialysis machine and I sat on a chair, next to her bed. The curtain was not drawn and was open to the rest of the ward, at Farah's request. Farah's mother was initially either present or nearby for the interview, although not actively involved. The analytic process posed one particular difficulty in being required to listen to an emotional exchange between Farah and a

friend (Sumayah)'s mother. The day of the interview was Farah's last day at the children's hospital, information which was not shared with me prior to the interview, and thus this interaction was an emotional goodbye. This also appeared to mark the moment where Farah came to the realisation that she would be leaving the children's hospital indefinitely. This left me feeling somewhat as an intruder on this special moment and also helpless because Farah was upset, despite my attempts to comfort and reassure her after the exchange.

Holistic Analysis

Table A14: Holistic analysis in relation to Farah's narrative

	Classification	Researcher Interpretation
Progression of plot (Gergen & Gergen, 1984)	Stable	In terms of narrative structure and development, Farah's story appears to be stable. This is because despite a mixture of happy and more difficult moments, there is not substantial evidence to suggest either a decline or progression in Farah's narrative. Rather, Farah's plot appears to be steady over her time at hospital and HS with a stable evaluation of the way she perceives and interprets her hospital experience. Although clearly valuing the relationships she has established at hospital, which she spoke about with enthusiasm, the general tone of Farah's evaluation of the events in her narrative, remained steady.
Genre of narrative: 1. Literary (Lieblich et al., 1998; Czarniawska, 2004) 2. Illness narrative (Frank, 1995)	1. N/A 2. Quest/ restitution narrative	I deem that Farah's narrative does not fit a traditional literary genre. Rather, I deem Farah's narrative to fit into a typology of tolerance, resignation and submission. Comments made in Farah's narrative, such as "feels the same all the time on here", "I've got through it with all the help" and "all this treatment. It's hard. But you have to deal with it" indicate Farah's acceptance. Furthermore, Farah's title of her narrative "Kidney Life" suggests her acceptance that her life is simply a reflection of living life with kidney problems, a perception that this is the just the way life is. At times during the interview, it seemed to me that Farah did not comprehend why I would be interested in her life, possibly because to her, it was simply a 'normal' life of a CYP with kidney failure. With regard to an illness narrative genre, I consider that Farah's story could be interpreted as either a quest or restitution narrative. A quest illness narrative could be considered due to Farah's acceptance of her way of life and way of being, whilst conversely a restitution illness narrative could be interpreted due to Farah's aim for a new kidney, which brought her numerous benefits including good health, no hospital and happiness.

Farah's narrative is characterised by acceptance of her medical condition and the mundaneness and routine of her life is the focus. However, I acknowledge that the context in which Farah's narrative was co-constructed, namely her last day at the children's hospital, may have influenced Farah's narrative and my resulting interpretation. Farah may have been distracted and disinterested during the interview, if it was not her principal priority at that time.

Narrative Summary

Table A15: Narrative summary of Farah's experiences of hospital and hospital school

	Interpretation
<i>Beginning</i>	Farah first came to hospital when she was approximately 3 years old. However, she could not remember from that time and so chose to begin her narrative when she was 10 years old. From the age of 10 to 14 years, Farah received a kidney transplant which she described in positive life-changing terms. She also described visiting a waterpark with her family, which she enjoyed, following her kidney transplant.
<i>Middle</i>	Over the past year, Farah has received dialysis treatment at the hospital, which meant going to a new ward, one which she had never been on before. During this time, she received hospital schooling. Farah described her worst experience of hospital and HS as when she had pancreatitis, which was very painful for her and required her to be in intensive care.
<i>End</i>	Farah explained that getting to know everyone on the ward, in particular nurses, playworkers and other hospitalised CYPs was the highlight of her hospital and HS experience. Farah spoke about her friendships, one in particular, which was evidently special to her. Farah described her relationships with others as like 'a big family' on more than one occasion. Farah expressed some anxiety regarding her imminent transfer to adult care.

Narrative Restorying

Table A16 outlines the interpretative process of restorying Farah's narrative. The chapters she identified herself have been utilised to frame the key events and experiences which occur during each time-frame.

Table A16: Farah's event and experience-centred narrative with additional researcher interpretation and commentary

"Kidney Life" ²			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative comments
Chapter 1: 10 to 14 years	Farah had a kidney transplant and went to a waterpark with her family (*best moment*)	<ul style="list-style-type: none"> "I was I had more energy... I grew. My hair got better my skin, everything was just like normal." "I was loving it. It was so much better. Less hospital, no machines, you can drink and eat whatever you want cuz I'm on a fluid restriction and I'm only allowed 500ml a day and we're limited with what we can eat, low phosphate and potassium. And when you have a kidney you can have anything" 	Farah described her happiness when she had her kidney transplant. Firstly, Farah explained how physically she had <u>more energy</u> , which she repeated, possibly indicating its importance for her. She also described the positive impact the transplant made to her <u>physical appearance</u> (height, hair and skin) and describes herself being 'normal'. Farah's happiness in relation to her transplant was also related to her <u>reduced attendance at hospital</u> . Furthermore, Farah considered there to be <u>fewer restrictions</u> when she had the kidney transplant in relation to food and drink, and there appears to be an element of <u>liberation</u> associated with Farah's experience of a kidney transplant.
	Farah had pancreatitis for two weeks (*worst moment*)	<ul style="list-style-type: none"> "Really bad. A lot of pain" "I went to intensive care for 3 days with it and I was on loads of morphine" 	Farah conveys her experience of pancreatitis in terms of <u>significant physical pain</u> . Farah also explained that her Mum stayed with her in hospital and that Farah's pain had a negative impact on her Mum.
Chapter 2: 15 – 16 years	Farah was required to change wards due to having dialysis treatment. Farah got to know everyone on the new ward	<ul style="list-style-type: none"> "Getting to know everyone. Like <i>properly</i> on dialysis and making friends" "Like before... I used to see them around like [name of boy] and Suzan. I never really got to know them. But now I got to know them. Always see [name of boy] in [name of entertainment plaza] and everything" "And me and Suzan are moving 	Farah identified that the past year since she has been on dialysis, has afforded Farah the opportunity to get to know <u>other hospitalised CYPs, on a deeper level</u> . Farah's consideration of these hospitalised CYPs as ' <u>friends</u> ' demonstrates the close relationships she has with them. Farah identifies <u>one particularly close friend</u> who she has known for a longer time, through their attendance at hospital. Farah also explains that one of her friendships is likely to <u>aid her transition to adult care</u> , as the two girls will be transitioning together. Farah explains that moving wards also meant getting to know unfamiliar nurses. Farah describes her relationships with others in the

² This title was given by Farah. This was in response to my interview question inviting her to think of a title for her story, relating to the story being akin to a book or a film.

“Kidney Life” ²			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative comments
		<p>together now so it’s more easier for (us/her)”</p> <ul style="list-style-type: none"> • “It’s <i>nice</i>. Like a big family.” 	hospital positively, describing it to be <u>like a family</u> . I interpret this to reflect the support and strength they provide for each other and represents Farah’s closeness to others on the ward.
	Leaving the children’s hospital to transition into adult care	<ul style="list-style-type: none"> • “Feel upset. But I don’t think it’s proper hit me yet... I think maybe when I’m going. Probably will” • “I dunno about [getting used to] the nurses and that cuz it’s all different all the time there because it’s <i>huge</i>” 	Farah expressed that she feels <u>sadness about leaving</u> the children’s hospital and that there are difficulties in <u>coming to terms</u> this. I interpret that Farah is daunted not only by the <u>size</u> of the new adult hospital, but also by the <u>different</u> environment, in which she perceives that she may not have the same nurses all the time, which may cause Farah to feel unsettled.
Future chapters	Farah at age 17 years in the new adult hospital	<ul style="list-style-type: none"> • “I’m hoping to... settle down in the [name of adult hospital]... Like getting used to it, like knowing the place.” • “I’m hoping I get a kidney... Happy... No more lots of hospital no more dialysis” 	Given the joy expressed when Farah had a kidney transplant, it was unsurprising to me that Farah was hoping to receive a kidney in the near future. Likewise, given the importance Farah placed on being accustomed to the staff at the children’s hospital, and the place itself, it was unsurprising that Farah was keen to become accustomed to her new (adult) hospital.
	Farah continuing to study at college	<ul style="list-style-type: none"> • “Level 2 cuz I’m on Level 1 now” 	Farah viewed a progression in terms of her vocational (hairdressing) skills development, which I interpret as positive.
	Long-term future when Farah is an adult	<ul style="list-style-type: none"> • “Driving. I dunno what else. Working... [Me: Would you be a hairdresser?] Hoping” 	Farah appears to want things for the future that perhaps other CYPs her age would also, e.g. driving. However, when Farah was asked about her future job (after she mentioned that she would be working), Farah indicated doubt about being a hairdresser, despite this being what she was working towards.

Themes

Using a thematic approach 7 themes were identified in relation to Farah's narrative, as represented in Table A17. Codes were initially identified based on Farah's original transcript (see Appendix 17) and these codes were then grouped into themes (see Appendix 17).

Table A17: Thematic Analysis - Key themes interpreted from Farah's narrative

Themes	Exemplary Quotations	Interpretation
1. Anticipation about transferring hospitals	<p>"Scared... Because it's something all new and new faces. It's bigger and I been here since I was 3."</p> <p>"In there, it's different all the nurses cuz it's bigger and everything"</p> <p>"Feel upset. But I don't think it's proper hit me yet."</p> <p>"It's not a party it's like... They just getting food. Not gunna celebrate"</p>	Farah was clearly anxious about leaving the children's hospital and transferring to adult care. She expressed that things would be different, e.g. the hospital size and the nurses. It is a particularly difficult transition for Farah as she has been at the children's hospital since the age of three. During the interview, Farah repeatedly emphasised to me that the gathering she was having was <i>not</i> a party. I interpret this to be indicative of Farah's perception that the gathering was not a celebratory or happy occasion.
2. Activities in hospital	<p>"Yeah they like on dialysis, [name of playworker 1] like she does like activities with us, sometimes we do like a mystery box, we have to put our hand in there and we have to guess what it is and whoever's got the most ten things whoever's got the most right gets a prize at the end... They put hair gel and everything"</p> <p>"Talk. Arts and crafts. Anything"</p>	Farah spoke of HS in terms of occasionally accessing it (over the past year and sporadically prior to this). The lack of HS's presence in Farah's narrative perhaps indicates that HS has not greatly impacted on Farah's hospital experience. Conversely, Farah spoke about the playworkers with passion and enthusiasm and it was evident that these adults were significant to her hospital experience. Farah spoke about the activities they did with her, e.g. shopping in the city centre, organising transition to the adult hospital, arts and crafts and the 'mystery box' activity which Farah enjoyed.
3. Support/relationships in hospital	<p>"My Mom... She helped me. And my Nan. All the time... Coming in. Getting me what I want and everything"</p> <p>"I knew Sumayah all along. Me and her were like <i>tight</i>. Because we used to stay on the ward and everything together."</p> <p>"Like when I'm ill and just fed up. They [Playworkers] Just like convince me and make me happy."</p> <p>"It's been hard. But at the same time I've got through"</p>	A predominant theme in Farah's narrative is the close relationships she has developed in hospital, which she described like a 'big family', in addition to the support she has received from her own family. Farah spoke about her positive relationships with other CYPCCs. During the interview, Farah distributed presents to other CYPs on the ward, which appeared to be important to her. Farah conveyed that she had one particularly close friend (Sumayah) in hospital and that they had known each other for a long time. In addition, Farah spoke about the nurses' support in

Themes	Exemplary Quotations	Interpretation
	it with all the help”	administering the correct medicines. Furthermore, she expressed the emotional support provided by the playworkers in elevating her mood when she feels low. ³
4. Benefits of kidney transplant and challenges without	<p>“You can drink and eat whatever you want”</p> <p>“No more lots of hospital no more dialysis”</p> <p>“I’m on a fluid restriction and I’m only allowed 500ml a day and we’re limited with what we can eat, low phosphate and potassium.”</p> <p>“I grew... My hair got better my skin, everything was just like normal”</p>	Another theme in Farah’s narrative is the marked difference between having a kidney (which she did previously) and not (i.e. presently). Farah described the sense of liberation regarding food and drink intake when she had a kidney, which contrasts with the consumption restrictions placed on her at present. Farah also referred to liberation in not having to attend hospital frequently to receive dialysis treatment. Farah also spoke about differences concerning her energy levels and physical appearance.
5. Uncertainty about the future	<p>“I’m <i>hoping</i> I get a kidney”</p> <p>“I dunno what else. Working [And then would you be a hairdresser?] Hoping”</p>	Although Farah was able to talk about what she wanted for her future, I interpret there to be elements of doubt and uncertainty in her narrative, with regard to the future.
6. Routine	<p>“I’m hoping to get a kidney, settle down in the [name of new hospital]”</p> <p>“Feels like the same all the time on here”</p>	Farah spoke about the routineness, and even mundaneness, of her hospital experience as well as hoping she would become accustomed to the new hospital. I interpret that for Farah, routine is connected to feelings of being settled, stability, security and comfort.
7. Medical intervention/treatment	<p>“A lot of pain”</p> <p>“They gave me the right treatment when needed and they been looking after me since I was small.”</p> <p>“Sometimes they used to stress me out. Like more and more medicine but they just do it for the right reason”</p>	Farah spoke about the physical pain associated with pancreatitis, which she deemed the worst moment in her hospital experience. Farah recognises the need for medical intervention and perceives doctors as the gatekeepers to this (“the ones in charge”). Although she has found the high quantities of medicine at times difficult, she appreciates the good intentions behind these medical decisions.

³ It must be noted that during the interview, Farah said goodbye to Sumayah’s mother after she approached. This was a very emotional, genuine and heart-felt exchange in which both Sumayah’s Mum and Farah were visibly upset. Sumayah’s Mum said comments such as, “We’ll never forget you Farah. You’re my *baby*”, which demonstrates the close relationships Sumayah has developed not only with individual hospitalised CYPs, but also their families. Sumayah’s mother invited Farah to spend time with Sumayah at her house fortnightly, which demonstrates the long-lasting nature of the close relationships also.

ROSE

Rose's interview took place on a children's cancer ward, where Rose was based. Most of the interview occurred on a bench in the corridor of the ward, near to her bed. Although the interview was not private, for example having a curtain drawn or being in a separate room, the ward was the quietest of all the wards in which interviews were conducted. There were several disruptions during the interview, and one longer interruption in which Rose was required to have eye drops. Toward the end of the interview, we moved location so that Rose was on her bed and I was next to the bed, so that the machine to which Rose was attached could be plugged in. Rose's mother was nearby further along the corridor at most points in the interview and spoke to me separately at occasional points. During analysis of Rose's narrative, there were two particularly difficult moments. Firstly, I had a strong emotional reaction when Rose mentioned a medical procedure of which I had had a negative experience. This therefore caused me to inevitably relive aspects of this personal experience, which was unpleasant. However, my self-awareness in this instance meant that I was able to take a physical and mental break and attempt to separate myself from Rose's experience of the event. Secondly, similarly to other participants, it was difficult to listen to and analyse Rose's description of her worst moment in hospital. She described the experience so vividly and in such detail that I felt real empathy with Rose and her mother, which had a negative impact on my wellbeing in that moment.⁴

Holistic Analysis

Table A18: Holistic analysis in relation to Rose's narrative

	Classification	Researcher Interpretation
Progression of plot (Gergen & Gergen, 1984)	Regressive → Progressive → Regressive	In terms of narrative structure and development, I interpret Rose's narrative to be a combination of both progressive and regressive narratives. Over the course of Rose's experience of hospital and HS, her narrative begins as <u>regressive</u> , when Rose first became ill with cancer. Rose underwent a lengthy medical investigative period marked by significant physical pain and a dramatic change to her life. Next, I interpret the narrative to become <u>progressive</u> , when Rose returned home, and resumed her normal routines and activities. Rose's family holiday to Switzerland is exemplary of this happy period, in which Rose had returned to full health. I interpret the final part of Rose's narrative, in which she experienced a relapse and suddenly became ill again, as <u>regressive</u> . Rose explained experiencing intense pain and having to go to hospital again, where

⁴ As the section on ethical considerations states (Section 3.12), I took measures to protect my own wellbeing as researcher during the data analysis procedures. I engaged in self-reflection in order to address my cognitive and emotional responses in addition to taking breaks as necessary, during the analytic process.

		she remained for 16 weeks continuously and was subject to considerable boredom.
Genre of narrative: 1. Literary (Lieblich et al., 1998; Czarniawska, 2004) 2. Illness narrative (Frank, 1995)	1. Comedy 2. Restitution narrative	From a literary perspective, Rose's narrative could be judged as being a <u>comedy</u> , due to the apparent pursuit for a common harmony, which I interpret to be her good health, despite numerous obstacles and complications, which occur throughout Rose's narrative. I also deem Rose's narrative to be akin to a ' <u>restitution narrative</u> ' as I interpret her view of illness as transitory, which has passed before and will pass again, with sufficient medical intervention, tenacity and support. Rose's narrative presents a distinction between her 'well self' when she is 'normal' and 'right' and engaging in her ordinary activities such as school, dancing and holidays and her identity when she is ill and not able to do these things. Rose's narrative appears to focus on returning to her former (and possibly 'truest') self, prior to illness.

Rose's narrative represents a complex journey of uncertainty, becoming ill, then recovering and returning to optimal health before finally facing the devastating reality of a health relapse.

Narrative Summary

	Interpretation
<i>Beginning</i>	Rose first became unwell at the age of nine years old and was admitted to hospital. Rose describes this year as eventful, not only becoming unwell and being admitted to hospital initially but then also transferring hospitals twice. Prior to this, Rose describes being a keen dancer and this past-time taking up much of her spare time. Rose explained that aged nine, she underwent numerous investigative tests in order to determine the cause of her ill-health. Rose reported that it took a long time to receive a diagnosis of cancer and she spent much time in hospital being very unwell.
<i>Middle</i>	When Rose was approximately 9 – 11 years old, Rose describes a period of going back home and returning to normal activities, as she tried to get back to full health. At this time, Rose received chemotherapy treatment and returned to school and dancing. Rose explained that she became 'free from leukaemia' and went to Switzerland to see family for Christmas. This was her best moment, as she was able to go skiing, which she had always wanted to do.
<i>End</i>	Since Rose has been 12 years old, she has experienced a relapse and has become unwell once more with cancer. For Rose, becoming ill again nine months after thinking she was well, has been the worst moment of her entire hospital and HS experience. Rose depicts this period of time as being in hospital and at times being "a bit bored".

Table A19: Narrative summary of Rose's experiences of hospital and HS

Narrative Restorying

Table A20 below outlines the interpretative process of restorying Rose's narrative. The chapters Rose identified have been utilised to frame the key events and experiences which occur during each time-frame.

Table A20: Rose's event and experience-centred narrative with additional researcher interpretation and commentary

"The Ups and Downs" or "What Will Happen Next?"⁵			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
Chapter 1: 9 years	Rose first started to feel unwell. She went to the doctors due to significant pain and a lump on her chest (*turning point*)	<ul style="list-style-type: none"> • "But the doctors at our doctors didn't believe us and thought things like I just didn't want to go to school so I was acting poorly and stuff like that" • "Being all not poorly at all so being normal kind of... It made me feel all fed up and sad... it made me feel quite really hurting everything hurt and it just didn't feel right" • "I was fine and I did loads of dancing and things like that and then I just started to feel poorly" 	Rose described when she first started to feel unwell, in which she appeared to have had a <u>lack of energy and strength</u> , e.g. being unable to attend school. Rose expressed that she was <u>not believed</u> by her GP regarding her symptoms. Rose felt considerable <u>pain</u> and " <u>didn't feel right</u> ", which I interpret to be indicative of Rose's comparison between her well ('right' or 'normal') self and her unwell self. Rose describes this period of starting to feel unwell as a <u>turning point</u> , which appears to be representative of the <u>significant life-changing</u> event which cancer was for Rose. She indicated the difference between when she was well, e.g. dancing frequently, to then feeling unwell and no longer being able to do these things.
Chapter 2: 9 years	Rose was admitted to hospital (near to where she lives).	<ul style="list-style-type: none"> • "They didn't know what to do so they did MRI scans and a CT scan" • "I didn't want to go to hospital but I didn't quite understand why I was taken into hospital. But I just felt so poorly I kind of knew that I needed to" 	Rose spent long in hospital undergoing medical investigations to find out why she was feeling unwell. Rose indicated that medical staff were unsure of the cause of her ill health and thus the diagnostic process was complex. Although Rose was reluctant to go to hospital and did not fully understand the reasons for going, the severity of her symptoms meant that Rose recognised the necessity of hospital.
	After testing, Rose was transferred to the hospital where she currently is, in which they carried out further medical procedures in	<ul style="list-style-type: none"> • "When I went in to have it [biopsy] done under anaesthetic they put a really big nose tube in... and they didn't <i>tell</i> me they were gunna put a nose tube in. so that was annoying." • "I didn't speak or eat for a week cuz it 	During further invasive medical procedures in hospital, Rose describes the experience of undergoing a biopsy. She emphasised that she was not told about the insertion of a large nose tube which she found "annoying". For Rose, <u>communication</u> therefore appears to be necessary to her care so that she is involved in happenings and knows what to

⁵ These titles were given by Rose. This was in response to my interview question inviting her to think of a title for her story, relating to the story being akin to a book or a film.

“The Ups and Downs” or “What Will Happen Next?”⁵			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
	order to make a diagnosis. Rose was very ill during her time in hospital.	was so horrible. It was so hurting... and achy and then when they took it out I ate loads of watermelon cuz I was so hungry... but I did feel really really <u>sicky</u> ”	expect. Rose also emphasised the <u>pain, sickness and restriction</u> (e.g. not being able to eat/speak for a week) involved with the procedures. The significant impact of the nose tube i.e. not being able to eat means that not being told of this in advance is particularly important.
	Rose was transferred back to the hospital near to where she lives	<ul style="list-style-type: none"> “I had some school from someone... she didn’t come much because she only knew I was there about half of the time cuz I didn’t feel well there at all.” 	When Rose was transferred again, she was not well. Rose did not receive frequent hospital schooling, as she states that the HS teacher did not know that she was there for the full duration. This suggests that the HS teachers were not informed of Rose’s presence in hospital.
Chapter 3: 9 – 10 years	Rose was able to go back home	<ul style="list-style-type: none"> “Next best one would be being getting home cuz after so long in hospital.” 	Returning home was Rose’s second best moment during her hospital experience. Her positive evaluation of this event is partly due to the length of time spent in hospital prior to going home and this was therefore particularly important for Rose, despite her “still being poorly” whilst at home.
	Rose started to feel better and returned to school and dancing	<ul style="list-style-type: none"> “Be getting better – so feeling not as sick. Getting back to school, getting back to dancing” 	I suggest that returning to her <u>normal routine and regular activities</u> was important for Rose. When asked, Rose affirmed that returning to dancing was important to her as she did the activity so frequently prior to becoming ill. Returning to such activities and returning to a sense of normalcy could be integral to Rose re-assuming her <u>identity</u> as a dancer.
Chapter 4: 10 – 11 years	Rose received chemotherapy treatment and was back at home	<ul style="list-style-type: none"> “So 10 til 11 is having all my chemo and stuff. And then that one will be chemo at home and trying to like get back to being alright” 	Rose indicates that receiving chemotherapy treatment was an important memory for her. I interpret that Rose perceives the process of getting better as an <u>active process</u> . This could be physically, in returning to her regular routine, but could also indicate a cognitive or emotional aspect of ‘trying’ to get better. Rose emphasised that although she was having chemotherapy, she was “still alright”.
Chapter 5: 11-12	Rose was ‘free from	<ul style="list-style-type: none"> “Before I got poorly we used to go to 	Rose expressed that she became ‘free from leukaemia’ and

“The Ups and Downs” or “What Will Happen Next?”⁵			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
years	leukaemia’ and went on a family trip to Switzerland where she went skiing for Christmas (*best moment*)	Switzerland twice three times a year at all the holidays to see my cousins and my cousin is 2 and I think my cousin was born while I was poorly... so we used to go and see them <i>loads</i> but suddenly we couldn’t see them so they have been to visit but it’s not like the same when they come to visit”	enjoyed a Christmas family holiday to Switzerland, which she deemed her ‘best moment’ from her hospital and HS experience. Rose stated that she was “fine and back to normal”, which suggests that Rose perceived that she had made a <u>full recovery</u> from illness. Rose’s use of the word “free” in reference to leukaemia could indicate both a physical recovery and an emancipatory element of this recovery. The holiday was an important trip for Rose because when she was ill she could no longer travel to Switzerland, as she was accustomed to doing and therefore meant a big lifestyle change for Rose and her family. Although her family visited England, Rose did not enjoy this as much as it does not equate to the adventure of going on a plane and skiing. This experience is particularly poignant for Rose as it marks the pinnacle of her good health and returning fully to normality.
Chapter 6: 12 years	Rose became ill again (*worst moment*)	<ul style="list-style-type: none"> • “Sad. Cuz I kind of before it happened because when I got poorly the second time I was fine I went home on the bus it was the second time I’d gone home on the bus at school cuz I didn’t get the bus much and when I got home it hurt there which was the same place so I thought. I kind of knew before it had happened that it was... It was probably likely to be the same kind of thing” • “I remember I was like this is really really hurting I can’t do anything this is really hurting. And then it started 	In contrast to Chapter 5, Chapter 6 marks a significant change for Rose when she became ill for a second time. This was particularly difficult for Rose because she had thought she was better and then faced the crushing reality that she was ill again. This appears to have been a <u>devastating</u> event for Rose, following the sheer happiness at Christmas with her family, to then becoming ill not long afterwards. Rose described that she <u>knew deep down</u> that she was ill again (a ‘sinking feeling’), before the doctors’ diagnosis and confirmation of the relapse. Rose described the significant pain she experienced. She also expressed uncertainty about whether she could go to the ward because she was “better but we didn’t know I wasn’t fully better”. This suggests a sense of limbo of having recovered, but simultaneously also not being fully better.

“The Ups and Downs” or “What Will Happen Next?” ⁵			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
		to <i>really</i> really really really hurt and then we just had to go to bed.”	Rose describes this as her <u>worst</u> experience of hospital and HS which is indicative of the sharp contrast between thinking she was better and then suddenly realising she was not well.
	Rose went to A & E after feeling unwell. Rose had a heart ECG, an x-ray and an Ultrasound. Rose was then taken to a ward	<ul style="list-style-type: none"> • “[The consultant] gave me morphine and lots of other painkillers ... she kind of whispered to Mum, Mum said is it like [name]. [name] is another boy here he is relapsed as well... and then she said probably and Mum kind of knew and then we got sent here” 	Rose stated that in hospital she received lots of pain relief. She also recalled a conversation between her mother and the consultant, in which Rose’s mother became aware of the likelihood of Rose’s relapse. Rose describes this conversation as <i>whispered</i> between the two adults, which suggests the adults may have wanted this conversation to be private, despite Rose’s overhearing.
	As a result of becoming ill for the second time, Rose has been in hospital for 16 weeks continuously	<ul style="list-style-type: none"> • “Like at home if I was bored... we could go for a walk ... we could go and have a picnic somewhere, we could paint, we could draw, but you can’t really do all of that here. You can draw but it’s not like there aren’t really nice pens or there’s not really enough space as well” 	Rose’s evaluation of her present situation, being in hospital, is characterised by <u>boredom</u> . She explained that although she is unwell, there are also times when she does not feel sick, and it is these times in particular when she becomes bored. Rose contrasts this to her life at home and the array of options she would have for keeping herself entertained.
Future chapters	In 3 months’ time, Rose will be having a bone marrow transplant (short-term future)	<ul style="list-style-type: none"> • “I’m hoping I feel better and I’m hoping that my bone marrow will work and so my bone marrow will be working and I will still be doing schoolwork and seeing friends but not going to school and still eating a clean diet cuz I have to eat a clean diet which is peeled fruit and veg only, you’re not allowed really weird stuff. Can’t have couscous as well” 	Following her <u>bone marrow transplant</u> , Rose explained that she would not be permitted to attend school for 100 days following the procedure and would therefore not enter Year 8 with her peers. Although Rose would not be attending school, she anticipated doing schoolwork and seeing friends, which is perhaps important to her as a means of maintaining a sense of normality. Rose emphasised that she hoped the transplant would be successful and that she would feel better. Rose’s commencement of a ‘clean diet’ suggests the importance Rose places on adhering to medical advice. Rose’s willingness to engage in <u>self-management</u> of her illness could also indicate a

“The Ups and Downs” or “What Will Happen Next?” ⁵			
Chapters	Key events	Experiences (exemplary quotations)	Interpretative comments
			sense of control in attempting to manage her health.
	Longer-term future Rose hopes that she will be healthy	<ul style="list-style-type: none"> “All better... Nothing really the matter. Having lots of friends, being able to do stuff like everyone else can do and not having to come to hospital” “I know that I’ll have to come to hospital for check-ups but not for anything else like at all... Yeah <i>hopefully</i>” 	Rose aspires to <u>be healthy</u> , as her priority. Although she recognises that she may have to attend hospital for check-up appointments, she hopes not to go to hospital for anything significant. Rose’s use of the word ‘hopefully’ which she stressed, implies <u>uncertainty</u> about the future. The existence of the <u>capacity for sudden and unexpected change</u> regarding Rose’s health, which is beyond her control, may impact her uncertainty about her future health status. Rose discussed the future in terms of social relationships, which would be expected of a CYP of her age. Rose also stated that she wants to be able to do things like everyone else, clearly making a <u>distinction between her life and that of her peers</u> . Rose may long to be like other children her age.

4.5.4. Themes

Using a thematic approach, 7 themes were identified in relation to Rose's narrative, as represented in Table A21. Codes were identified and then grouped into themes (see Appendix 17 for exemplars of this process). Table A21 details each of the 7 themes with exemplary quotations used to evidence interpretations.

Table A21: Thematic Analysis - Key themes interpreted from Rose's narrative

Themes	Exemplary Quotations	Interpretation
1. 'Normal' self and routine	<p>"And we usually go and see my Granny and Grampy every day"</p> <p>"Before I was poorly I had I was really I did 23 hours of dancing a week and I danced every day after school except Wednesday and I did all kinds of different dance – I did ballet, tap, disco, ballroom, latin, rock n roll, cheerleading, cheer comp, Scot – no Irish, street, so loads of stuff"</p> <p>"Being all not poorly at all so being normal kind of"</p>	<p>A predominant theme in Rose's narrative is the contrast between her 'normal' self and routine, and when she is unwell. Rose's routine when healthy involved visiting her grandparents, going abroad and dancing. Rose's use of words such as 'normal' contrasts with 'not being right' which suggests two divergent poles. Rose summarised her experience of hospital and HS as "a bit sad", which I interpret as reflective of feelings of grief and loss experienced as a result of her identity change and not being her version of 'normal'. Rose spoke about being like 'everyone else' in the future which again indicates her perception of 'normal' and 'not normal'.</p>
2. Hospital school	<p>"I haven't had any lessons really until this week cuz all the teachers haven't been coming for some reason."</p> <p>"But the Science teacher if she can't come in the afternoon sometimes if she's busy she pops her head in on the morning and says I can't come today is that alright"</p> <p>"Their lessons are good because they enjoy teaching them... we made flapjacks as one of my science lessons and she understands that sometimes we might not want to do it, but if you make it fun it's more likely to want to do it"</p>	<p>Rose perceived uncertainty/unpredictability about HS lessons. Rose stated that she only had some lessons (German and Science) and not others. This had implications not only in terms of Rose not knowing the topics being covered in the other lessons but also about how she perceived the teachers. The Science and German teachers were spoken about fondly and by name and Rose perceived that the teachers enjoyed teaching the subjects. Rose also enjoyed the content of these two lessons. Moreover, Rose appreciated the efforts to make the lessons enjoyable which encourage CYPCCs to engage, even if they are reluctant at first. Conversely, the other teachers were less well known and not referred to by name. Rose's comments suggest that she perceives that the teachers choose not to come, without informing her, which she perhaps resents. The flexibility of the HS schedule is highlighted e.g. the Science teacher rearranging lesson times. Rose's boredom whilst in hospital could be</p>

Themes	Exemplary Quotations	Interpretation
		associated with her lack of consistent hospital schooling.
3. Communication with adults	<p>"They put a really big nose tube in my nose and they didn't tell me they were gunna put a nose tube in. so that was annoying."</p> <p>"She kind of whispered to Mum, Mum said is it like [name]. [name] is another boy here he is relapsed as well quite similar timing and then she said probably and my Mum kind of knew and then we got sent here"</p>	Rose spoke about communication with adults, in terms of HS teachers and medical professionals. Rose identified that when the Science teacher is unable to teach her as planned, she ensures this is communicated to Rose, which Rose appreciated. Rose compared this with other HS teachers, who perhaps did not arrive as scheduled, but did not inform her of this. Rose also referred to adults' lack of communication in terms of her medical care, for example not being told about the insertion of a nose tube and being excluded from a conversation about her health.
4. Pain	<p>"I couldn't touch it [lump on chest], it hurt <i>all</i> the time"</p> <p>"Then I had a lumbar puncture but I was being sick. The only way I could sleep was with my Mum holding my back it hurt so much and I couldn't really sleep cuz it hurt too much"</p> <p>"It was so hurting and hurting and achy... I did feel really really sick"</p> <p>"I remember I was like this is really really hurting I can't do anything this is really hurting. And then it started to <i>really</i> really really really hurt and then we just had to go to bed."</p> <p>"I couldn't get to sleep all night and then at 2 o'clock I ended up going to A & E it hurt so much"</p>	Rose referred to the lengthy and complex diagnostic period in which doctors were unsure of the cause of her symptoms. Moreover, at the first onset of feeling unwell, Rose reported that doctors did not believe her. Associated with this complex diagnostic period was a strong theme in Rose's narrative of pain. Rose refers to pain and sickness often in her narrative, relating to both procedures in the diagnostic period and as a result of her symptoms relating to her diagnosis of cancer.
5. Compliance and self-management	<p>"I didn't want to go to hospital but I didn't quite understand why... But I just felt so poorly I kind of knew that I needed to"</p> <p>"I have to eat a clean diet which is peeled fruit and veg only, you're not allowed really weird stuff. Can't have couscous as well... I'm not sure why... Yeah it's very weird... There's lots of other stuff as well"</p>	Rose adhered to medical intervention, e.g. initially going to hospital, because despite her reluctance, the pain was so severe that Rose realised the necessity of going to hospital. Furthermore, Rose actively followed medical advice to facilitate her recovery, despite considering some dietary requirements strange. This may represent Rose's attempt to have some control over her health.

Themes	Exemplary Quotations	Interpretation
6. Support and Comfort	<p>"She's looked after me. She's slept with me every night in hospital since I was in and she just helps me"</p> <p>"He's only missed one x-ray and I've had at least 60 probably... And MRI scans and CT scans as well"</p> <p>"I've got some favourite nurses and doctors... nurses are Amazing [name of nurse], Pretty Awesome [name of nurse], Ninja [name of nurse], Squeaky [name of nurse]... Cuz they kind of understand you and pay more attention but with the other nurses they sometimes just kind of do their job and that's it kind of thing. Cuz [name of nurse]... he's kind of funny and he sometimes does silly stuff"</p>	<p>Support and comfort appears to be a theme in Rose's narrative. Rose spoke of her family often, in particular her Mum, her maternal grandparents and family in Switzerland, who were always referred to positively, in terms of enjoyment, holidays and support. Rose referred to the importance of her grandparents in not only supporting her Mum, who appears to be Rose's sole carer, but also being 'like parents'. Rose also referred to her 'teddies' as sources of support as she has had them since she became unwell, and they have been present at the majority of her scans. Regarding medical staff, Rose identified favourite doctors and nurses, some of whom she referred to affectionately with nicknames. As with HS teachers, Rose differentiated between her favourite nurses and other nurses. Rose identified that some nurses 'understood' her, paid attention to her and were funny and silly, which she contrasted to other nurses who she perceived to simply do their job.</p>
7. Insecurity re: health status	<p>"I (thought I) was better and then I got poorly again"</p> <p>"Cuz there are lots of ups and downs"</p> <p>"Maybe 'Will it Stay the Same?' ... Either 'the Ups and Downs' or 'What Will Happen Next?'"</p> <p>"I'm hoping I feel better and I'm hoping that my bone marrow will work"</p>	<p>Rose identified considerable changeability in her narrative, partly due to the unpredictability of her health. The titles Rose ascribed to her narrative and the use of the words 'hopefully' and 'hoping' indicate this variability and also uncertainty about her future health. This perceived unpredictability is likely to be due to the swiftness with which she went from being in good health to a relapse and being hospitalised.</p>

SAJID

Sajid's interview took place in the afternoon on a ward with three other children. When I arrived Sajid was receiving physiotherapy and so I waited until he was ready before the interview occurred. Sajid was expecting me, having met me the previous day and was looking forward to the interview. In the bay directly next to Sajid was a young boy of about 6- 8 years old who was screaming and moaning loudly during some periods of the interview. Sajid's mother was present throughout the interview, sitting on the bed with Sajid, whilst I was sat on a chair next to the bed. Sajid's Mum actively contributed during the interview⁶. During the analytic process regarding Sajid's

⁶ Unlike the other interviews, Sajid's mother played a very active role in the interview. She played a unique role in the interview, switching from positively contributing to and supporting her son with his

narrative, there were particularly difficult aspects. Firstly, it was challenging for me to hear the distressed moans and screams from the child in the next bay, which was emotionally distressing for me, partly due to the loud volume and intensity of the screams. Moreover, the screaming obscured some of the speech in the interview. Although I provided support, reassurance and comfort for her during the interview, it was difficult to listen not only to challenging times for Sajid, but also for his mother as a parent of a CYPCC. Lastly, whilst analysing Sajid's narrative, I was overcome by his bravery. I had a strong outward emotional reaction to his response to adversity and the fact that despite deterioration in his health, Sajid still perceived that others' health conditions were worse than his own. I was awestruck by his positive response, which I found inspiring on a personal level. Rather than focusing on the negative, Sajid looked forward to enjoying a 'new life'.

Holistic Analysis

Table A22: Holistic analysis in relation to Sajid's narrative

	Classification	Researcher Interpretation
Progression of plot (Gergen & Gergen, 1984)	Progressive	In terms of development of Sajid's narrative, I found it difficult to interpret. On the surface, Sajid's appears to be regressive, particularly as over the course of his narrative, his health deteriorates significantly. However, after much deliberation I find Sajid's narrative to be <u>progressive</u> for the following reasons. Firstly, throughout his narrative, Sajid speaks about a development and progression in terms of how he has come to understand his condition and his treatment and how this has influenced the acceptance of his health status. This suggests a progressive 'coming of age' type story in which the protagonist undergoes a transformation. Secondly, Sajid speaks of being 'sad' at the beginning of his story and 'happy' at the end because he knows he will soon receive a bone marrow transplant which will transform his life for the better.
Genre of narrative: 1. Literary (Lieblich et al., 1998; Czarniawska, 2004) 2. Illness narrative (Frank, 1995)	1. Tragedy 2. Quest narrative	Sajid's narrative could be deemed as a <u>tragedy</u> based on the number of unfortunate and successive events that have happened to him throughout the narrative, and also the relatively few peak moments of significance. Despite the tragic prominence, I judge Sajid's narrative to be a ' <u>quest narrative</u> ' based on his knowledge acquisition not only in relation to his own condition, but also others. Sajid's active knowledge seeking about other people's medical conditions demonstrates Sajid's recognition of his illness experience as an opportunity. In finding out about other medical conditions, Sajid has concluded that his condition is not 'the worst', which may have

narrative to in reality, telling her own personal narrative, from her perspective as a parent of a CYPCC. It was interesting for me to hear her story, which she clearly needed to tell, and at times I had to resist the temptation to ask her further questions about her parent role and to explore this further. As the role of the parent and 'parent narratives' are not the focus of the present research, a clear distinction is made between the contributions Sajid's mother makes in relation to Sajid's narrative and her own parent narrative. To this end, although none of her comments have been discarded, those not contributing directly to Sajid's narrative, are represented in Appendix 18 for reference and transparency, and have not been analysed as they are irrelevant to the RQs.

		also helped with his acceptance of his illness and related lifestyle.
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Sajid's experience of hospital and HS can be characterised by development in knowledge and understanding. Sajid's pursuit of knowledge about his own condition and other conditions has given him a new perspective about how he relates to his medical condition.

Narrative Summary

Table A23: Narrative summary of Sajid's experiences of hospital and hospital school

	Interpretation
<i>Beginning</i>	Sajid was 5 years old when he was diagnosed with severe combined immune deficiency. Although very young at the time, Sajid found the event 'upsetting' because prior to the diagnosis, he felt he was a 'normal boy'. At this time, Sajid did not understand much about his condition and described hiding in the toilet because he did not want to receive the prescribed medical treatment.
<i>Middle</i>	When Sajid was 8 to 11 years old, there was a period of change in which he started to become accustomed to his treatment. During this time, Sajid experienced his best moment during his time at hospital and HS, which was going home after being hospitalised for some time. Sajid described going home as exciting and something which he had looked forward to.
<i>End</i>	During the period of 11-13 years Sajid made an important decision to have a bone marrow transplant. This was a daunting decision for Sajid as he was scared by the uncertainty of the implications of this procedure. Since the age of 11, Sajid's health has deteriorated considerably, which has been difficult for him and his family. Sajid describes his worst moment of his experience of hospitalisation and HS as spending 5 months continuously in hospital. Sajid looked forward to receiving a bone marrow transplant in the coming four months, which he anticipated would be life-changing.

Narrative Restorying

Table A24 outlines the interpretative process of restorying Sajid's narrative. Exemplary quotations relating to Sajid's evaluations of these events and experiences are included, in addition to my own interpretative comments.

Table A24: Sajid's event and experience-centred narrative with additional researcher interpretation and commentary

"A Happy Ending" ⁷			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative comments
Chapter 1: 5 – 8 years	Sajid received a diagnosis of a severe combined immune deficiency when he was 5 years old	<ul style="list-style-type: none"> • "Upsetting. Because I thought I was a normal boy like everybody else" • "Apparently I used to always hid myself in the toilet ... Cuz I feel like oh ok I'm gunna have it but really I thought I don't really want it" 	Although Sajid was young when he was diagnosed, it was 'upsetting' for him because it <u>changed the way he viewed himself and his identity</u> , from being 'normal' like everyone else to no longer being this way. Sajid used to hide from treatment which may indicate that although wanting to outwardly convey courage, inwardly Sajid did not want to have the treatment.
Chapter 2: 8 – 11 years	Sajid became accustomed to the immunoglobulin treatment he receives for his condition	<ul style="list-style-type: none"> • "I started to get used to my treatment to help me with my condition. Every... fortnight I have my immunoglobulin⁸" • "It's basically a thing where it boosts... your immune system up so your body doesn't reject" • "First I didn't know why... and now I understand what it is ...and what it does" 	With his mother's support Sajid explained the nature of the treatment which suggests that his <u>knowledge and understanding about his immunoglobulin treatment has increased</u> , which he too acknowledged. Sajid was also aware of the <u>benefits of his treatment</u> . Prior to becoming used to it, Sajid used to become panicked and stressed by the treatment, which he no longer does. Therefore Sajid's knowledge and understanding has positively contributed to his <u>treatment compliance</u> and <u>anxiety levels</u> .
	Sajid was permitted to return home after staying in hospital (*best moment*)	<ul style="list-style-type: none"> • "Most people when they end up in hospital all they wanna do is go home... No matter even if they've just been in for a minute" • "It's boring staying in hospital... you don't wanna hang around very long" 	Sajid described going home after a period in hospital as being his <u>best</u> moment of his hospitalisation and HS experience. This suggests that Sajid <u>dislikes being in hospital</u> and perceives this to be the case for everyone. He described hospital as <u>boring</u> and not somewhere one would want to stay. Sajid looked forward to the doctor telling him that he can leave hospital and go home.
Chapter 3: 11 – 13 years	Sajid decided to have a bone marrow transplant.	<ul style="list-style-type: none"> • "I was scared –scared on what would happen and what would the treatment be like" 	Sajid expressed that he was <u>frightened</u> about his decision to have a bone marrow transplant, due to degrees of <u>uncertainty</u> regarding the outcome and implications of the transplant.
	Sajid's health deteriorated	<ul style="list-style-type: none"> • "When your health goes worse... little things can turn into big things... Like 	Sajid explained that a drawback of his health deteriorating is that relatively <u>minor infections can turn into something worse</u> , which

⁷ This title was given by Sajid's Mum. This was in response to my interview question inviting Sajid to think of a title for his story, with which he struggled. Sajid agreed that this choice of title was appropriate for his story and was able to explain why he thought it was fitting, with reference to his experiences.

⁸ Immunoglobulin is a blood product used in the treatment of CYPs with complex immune deficiency disorders, to prevent life-threatening infections.

"A Happy Ending"			
Chapters	Key Events	Experiences (exemplary quotations)	Interpretative comments
		(osteomyelitis) can turn into lymphoma... At first I was admitted with (osteomyelitis) for 5 months... two weeks later they gave me this new diagnose cuz (osteomyelitis) is like a little thing... some people just say oh you've just got (osteomyelitis) you don't need to worry about that but... you don't know if you should worry about it because it can turn into something major serious which nobody knows"	for him had happened. This suggests that Sajid may perceive an <u>increased vulnerability</u> when his health is in a worsened state. Sajid's statement that 'some people' say that minor infections may not be anything of concern, is interesting. I interpret Sajid's feeling of ' <u>you don't know</u> ' to suggest that he perceives that other people may not truly understand what he experiences as a result of his condition. This may indicate a sense of being alone or difference. Furthermore, Sajid's comments suggest <u>uncertainty/unpredictability</u> associated with his condition, in that smaller infections may deteriorate.
	Sajid spent 5 months in hospital before he could return home (*worst moment*)	<ul style="list-style-type: none"> • "Devastated. Stressed. And felt like I can't manage this and I just wish I was on oral...I wish I was just on an oral antibiotics" 	Sajid's worst moment during his experience of hospitalisation and HS was recently spending a long period in hospital, in which he felt 'stressed' and 'devastated'. Sajid reached a point where he felt he could no longer manage the treatment demands.
	Sajid could not have a bone marrow transplant because he was diagnosed with lymphoma (*turning point*)	<ul style="list-style-type: none"> • "[Mum: Supposed to in May supposed to go to London to have a bone marrow transplant but that week the same week he had this diagnosed and everything just... Everything turned out and we were transferred]" 	Sajid was expecting to have a bone marrow transplant this year, but it did not happen due to his becoming ill and receiving a diagnosis of lymphoma. From Sajid's mother's comments, I interpret that the family experienced <u>disappointment</u> , as they had been looking forward to the transplant ("getting all of this behind us") and it did not happen due to Sajid's ill-health.
Future chapters	Aged 14-18 years, Sajid imagines he will be enjoying his life	<ul style="list-style-type: none"> • "A boy enjoying his life... Not going through anymore treatment again not having what used to have and just enjoying himself" 	Sajid describes his future in terms of <u>enjoyment</u> and <u>freedom from hospital treatment</u> . Sajid's vision for his short-term future is in light of his upcoming transplant, which he views will dramatically <u>change</u> his life ("a new life"). Sajid appears to associate enjoyment with not receiving hospital treatment.
	When Sajid is aged 18 – 24 years, he imagines he will still be enjoying his life	<ul style="list-style-type: none"> • "All the nurses will be old and saying did you remember that boy? He used to come for treatment? And they said yes... brings me back a lot of memories" 	Sajid describes his young adulthood as still enjoying his life and no longer receiving treatment. Sajid suggests that nurses will reflect fondly on his journey and how he used to receive hospital treatment as a child and how he has developed as an adult with a family.

Themes

Using a thematic approach to analysing data, 7 themes were identified in relation to Sajid's narrative, as represented in Table A25. Codes were initially identified based on Sajid's original transcript and these codes were then grouped into themes (for exemplars of this process see Appendix 17). Table A25 details each theme with some exemplary quotations.

Table A25: Thematic Analysis - Key themes identified from Sajid's narrative

Themes	Exemplary Quotations	Interpretation
1. Knowledge and understanding	<p>"I didn't know what was gunna happen... but now I understand it what I gotta go through and what I've got to have done."</p> <p>"Change. Cuz first I just used to cry and cry and thought oh what am I guna have cuz I didn't <i>understand</i> what was gunna happen but now I understand"</p> <p>"And not just my condition other conditions, what other people go through... I know that other people's conditions are worse than me like. Cuz I thought I was just the only one who had a worse condition because my Mom told me it was the condition you've got is really serious but I experience that it's not just my condition that's worse there's others other people have got worse conditions"</p>	Knowledge and understanding is a key theme that recurs often in Sajid's narrative. Sajid's understanding about his own medical condition was associated with Sajid becoming accustomed to his treatment, rather than the treatment inducing anxiety and/or fear for him. Furthermore, Sajid spoke in detail about his knowledge of other health conditions as a result of his own exploration, due to people he had encountered in hospital. Learning about other people's conditions has changed the perspective from which Sajid views his own condition. This is perhaps a coping strategy for Sajid, in helping Sajid to accept the nature of his condition and perceive it as not the worst, compared with others.
2. Uncertainty	<p>"I was scared –scared on what would happen and what would the treatment be like"</p> <p>"Like when your health goes worse you can get little things can turn into big things"</p> <p>"You don't know if you should worry about it because it can turn into something major serious which nobody knows"</p>	Sajid spoke about uncertainty regarding his health and the fact that smaller infections could escalate into more serious ones. Furthermore, the uncertainty of Sajid's health can impact on medical intervention e.g. his diagnosis of lymphoma meant that Sajid was unable to have a bone marrow transplant. Sajid also spoke about the uncertainty and associated fear involved when making important decisions about his healthcare.
3. Other people	<p>"Some people just say oh you've just got (osteomyelitis) you don't need to worry about that but some people , you don't know if you should worry about it"</p> <p>"People probably if I wasn't people sometimes say oh why's</p>	In Sajid's narrative, he appears to be very aware of himself in relation to other people. When diagnosed, Sajid was upset because he thought he was a "normal boy like everybody else", which perhaps suggests his longing to be like others as well as his perception

Themes	Exemplary Quotations	Interpretation
	<p>he not climbing on trees, they might probably think he might have a problem climbing a tree, but really it's not cuz he's got a problem it's probably because he's scared"</p> <p>"Before I learned how to ride a bike I used to lie to people saying I can ride a bike ... Cuz probably I didn't want to embarrass myself and I don't like being embarrassed"</p>	<p>of himself as different. Sajid displayed a heightened awareness about what other people might think or say about him. Furthermore, he perceived that other people <u>do not know</u> or understand his condition. Sajid seems to not want others to think that he has a 'problem' and is unable to do something, but rather is scared, possibly due to physical limitations. Sajid cares about other people's perceptions to the extent that he lied about not being able to ride a bike, to avoid embarrassment.</p>
4. Going home	<p>"Because it's boring staying in hospital quite long and you don't wanna hang around very long. The excited bit when I the exciting bit of the hospital is when the doctors come and tell you whether you can go home or not"</p> <p>"Because I spent five months to go home from hospital"</p> <p>"[Mum: Cuz he wasn't making any recovery... through IV... and two three hours four hours which they couldn't facilitate that at home. And the timing – 6 o'clock in the morning 12 o'clock at night... some things needed bloods before they had to give the medicine so I can understand from their point of view]"</p>	<p>Sajid expressed that going home was a significant aspect of his hospital and HS experience, so much so that the nature of both his best and worst moments were centred around going home. Sajid disliked staying in hospital for long periods and wanted to get out as soon as possible. Sajid looked forward to being told that he could go home by the doctors. I interpret the impact of treatment demands to be a contributing factor to the importance of going home for Sajid. This is because during Sajid's time in hospital, the treatment demands have been so great, that it can be particularly stressful and unpleasant for him.</p>
5. Adults in hospital	<p>"They've been supporting me through for 5 months... By encouraging me to say look you can do it you will get better"</p> <p>"[Mum: The consultants... they've known him since he was 5]"</p> <p>"Cuz they've been supporting me and helping me doing all the right things and helping me to get better... What medicines should I have... and making sure I'm well and healthy. And doing the right things like look you gotta go for an MRI... you gotta have an operation on your leg"</p>	<p>Sajid spoke about the important role of adults in hospital, in terms of his experience of hospital and HS. In Sajid's narrative, nurses and playworkers played a supporting role, in encouraging him when he is unwell. Sajid indicated that hospital consultants were also important as they made medical decisions to help him to be healthy. HS teachers appeared to have a smaller presence and have less impact on Sajid's narrative than medics. Furthermore, Sajid and his Mum seemed not to have met many HS teachers.</p>
6. Parental presence, support and	<p>"They've been staying day in day and night since for 5 months."</p> <p>"Cuz they've been helping me get</p>	<p>I interpret that Sajid likes his parents staying with him in hospital and appreciates their physical presence and</p>

Themes	Exemplary Quotations	Interpretation
knowledge/care	<p>in get in and out of hospital all the time”</p> <p>“Supporting me since my diagnosis”</p> <p>“I think like my Mom and Dad are nurse specialists because they do everything like my feeds, the IVs”</p>	<p>support. Furthermore, Sajid regards his parents as a vehicle through which medical help is accessed. Sajid perceived his parents as omniscient pseudo-nurses, because of their ability to administer necessary medical procedures to help him.</p>
7. Positive thinking	<p>“Thinking of having a bone marrow transplant which will change life”</p> <p>“It’s a boy who starts very sad at the beginning but ends up happy at the end... cuz I know after this I’m gunna be having a new life after 4 months after December”</p> <p>“The good thing now I can ride a bike. Even though I’m not well I can ride a bike without stabilisers. Actually it’s quite big as well...”</p>	<p>I interpret positive thinking to be a key theme in Sajid’s narrative. He spoke about a “new life” following an imminent bone marrow transplant, and based his “happy ending” on this key upcoming event. As well as thinking positively about his future, Sajid also thought positively about his achievements and accomplishments, for example celebrating that he could ride a large bike.</p>



