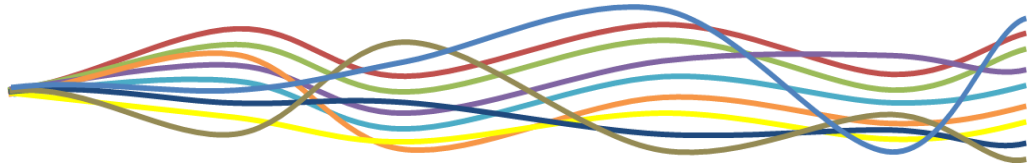# Stories of survival

Exploring long-term psychosocial well-being in childhood survivors of acute life threatening critical illness:
A multiple-case study

Joseph C. Manning

RN (Child Branch), MNursSci (Hons), PGCert Paediatric Critical Care

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Abstract

Background: Childhood critical illness is characterised by a rapid and potentially catastrophic loss of physiological reserve caused by a wide variety of illnesses and injuries. In the Western world, death from childhood critical illness is rare due to advances in paediatric intensive care (PIC) provision, medicine, technology and public health. However, surviving PIC can expose children and their families to a complex array of physical, psychological and social problems. Physical disability, chronic illness, delirium, and stress symptoms have been reported to manifest in the immediate to short-term (<six months post-PIC). Existing research has focused on quantifying the outcomes and impact of surviving childhood critical illness. Furthermore, decontextualised, pathologised, and uni-dimensional platforms to inquiry are the dominant approaches used. Collectively, this has impeded understanding of how childhood survivors construct and experience long-term (≥ six months post-PIC) psychosocial well-being.

Aim: This study aimed to explore how long-term psychosocial well-being is described, experienced and constructed by PIC survivors within the context of their lives.

Methods: A longitudinal, qualitative, multiple case study approach was used. Nine case studies were formed around a heterogeneous group of nine child and adolescent PIC survivors of an acute life-threatening critical illness (aged six-16 years), admitted to a single UK Paediatric Intensive Care Unit (PICU) at least six months previously. A further 23 significant others, including family members, health professionals and teachers, were identified by the PIC survivors to participate. Each case, bar one, was explored longitudinally over a six-month period collectively providing a follow-up period of six to 20 months post-PICU discharge. Data were collected from October 2012 until July 2013 and included 42 data collection visits. A flexible toolbox of qualitative methods (interviews and art-based approaches) was used to capture stories and accounts. Collectively, 33 hours of audio data and 427 images were collected. Data were analysed sequentially that provided insights into psychosocial well-being from the individual, within the case, and across cases. Both abductive and inductive

analytical approaches were used that included narrative psychological analysis, correspondence and pattern matching, and aggregating of case findings.

Findings: Findings from survivor accounts illuminate multifaceted and complex storied experiences. Stories were distinctive, varying in how they were constructed as well as in content, with differing biographical, experiential and aspirational accounts. These remained grounded in survivors' day-to-day lives involving vibrant imagery of life events, contextual factors and prosperities. However, adversities also featured through reports of amnesia, uncertainties, traumas, contemplation of death and dying, and stigma, which appeared to collectively direct constructions of psychosocial well-being.

From exploring within each case study, the context of PIC survivors' lives appeared complex, featuring ongoing adversities, chaos and change. Stories diverged between survivors and significant others as untold and hidden narratives emerged. However, shared stories also appeared, with a distinct focus on future aspirations and recovery. Shared residual traumas and adversities also featured, with narratives of sacrifice and protection being told, that in turn exposed significant others to additional adversity.

Findings from across contexts identified multifarious imagery with interwoven and intricate stories that illuminated the complexity of survivor experiences and lives. However, amongst this chaos, common themes from across PIC survivor stories were evident. Themes included: disrupted lives; exposure to death and dying; mediation between different social worlds and identities; and the focus on getting on with life. Through aggregating instances across whole-cases, the inter-relational nature of long-term psychosocial well-being was highlighted.

Collectively, findings identify that PIC survivors construct long-term psychosocial well-being within the context of their lives as a paradox; a state of disruption and flux, and an inter-relational and dynamic entity.

Conclusion: Childhood PIC survivors' stories are complex and identify numerous challenges and adversities that are faced when attempting to readjust to life in the long-term post-PICU. Mediation between psychological and social worlds can expose survivors to both negative and positive well-being. However, biographical,

individual, familial, social, and wider societal influences also appear significant in how PIC survivors construct and experience psychosocial well-being in the longer term. These novel insights into this unexplored phenomenon challenge existing theoretical propositions from the literature and provide a platform for further inquiry.

Scholarly outputs from this thesis

Peer reviewed papers:

Manning, J.C., Hemingway, P. and Redsell, S.A. (2014) Long-term psychosocial impact reported by childhood critical illness survivors: A systematic review. Nursing in Critical Care. 19. pp. 145–156. Doi: 10.1111/nicc.12049

Manning, J.C., Hemingway, P. and Redsell, S.A. (2014) Protocol for a longitudinal qualitative study: survivors of childhood critical illness exploring long-term psychosocial well-being and needs – The SCETCH Project. BMJ Open 2014;4:e004230 doi:10.1136/bmjopen-2013-004230

Published abstracts:

Manning, J.C, Hemingway, P. and Redsell, S.A. (2014). Long-Term Psychosocial Well-Being Following Acute Life Threatening Critical Illness: Exploring Childrens' Narratives of Survival. Pediatric Critical Care Medicine, 15. p.31.

Manning, J.C., Hemingway, P. and Redsell, S.A. (2013) Long-term psychological and social impact reported by childhood critical illness survivors: A systematic review and thematic synthesis. Archives of Diseases in Childhood. 98(Suppl 1), p.A31.

Conference presentations and posters:

Manning, J.C., Hemingway, P. and Redsell, S.A. (2014) Long-term psychosocial well-being following acute life threatening critical illness: Exploring childrens' narratives of survival. World Congress for Pediatric Intensive and Critical Care, Istanbul, Turkey.

Manning, J.C. (2013) The SCETCH Project Study Protocol: Survivors of Childhood Critical Illness; Exploring and Understanding Long-term Psychosocial Well-being & Needs In: Children's Nursing Research Conference. Children's Nursing Research Unit, Alderhey Children's Hospital, Liverpool, UK.

Manning, J.C., Hemingway, P. and Redsell, S.A. (2013) Surviving Childhood Critical Illness: A thematic synthesis of qualitative literature exploring long-term

psychological and social impact In: <u>2nd Paediatric Nursing Association of Europe (PNAE) Congress on Paediatric Nursing</u>, Glasgow, UK.

Manning, J.C., Hemingway, P. and Redsell, S.A. (2013) Long-term psychological and social impact reported by childhood critical illness survivors: A systematic review and thematic synthesis. In: <u>Royal College of Paediatrics and Child Health (RCPCH) and Europaediatrics Conference</u>, Glasgow, UK.

Associated prizes and awards:

2014- Shortlisted (Highly Commended) - WellChild Nurse of the Year Award. WellChild the national charity for sick children, UK.

2014 - European Society for Paediatric and Neonatal Intensive Care (ESPNIC) Nursing Fellowship. Sophia Children's Hospital, Erasmus-MC, Rotterdam, Netherlands.

2014 - Pediatric Critical Care Medicine Top Abstract Award. 2014 WFPICCS World Congress on Pediatric Intensive & Critical Care, Istanbul, Turkey.

2013 - Best Poster Presentation Prize. Children's Nursing Research Conference, Alderhey Children's Hospital, Liverpool, UK.

2011 - Translational Research Fellowship*. University of Nottingham, UK.

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This thesis is dedicated to: the nine child and adolescent survivors who were central to this study, there would have been no project without you - your stories have and continue to inspire me; and to my grandfather, Raymond Dowsett, it was your passion for education and learning that has motivated me to pursue my academic goals.

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Glossary of terms and abbreviations

<	Less-than
>	Greater-than
Adversity	A state or instance of serious or continued difficulty or misfortune.
Agency	Capacity of individuals to act independently and to make their own free choices.
ASSIA	Applied Social Sciences Index and Abstracts
CIES	Children Impact of Event Scale
CINAHL	Cumulative Index to Nursing and Allied Health Literature
Communion	The union of individuals in a close, caring, and communicative relationship.
dB	Decibel
EMBASE	Excerpta Medica Database
HRQoL	Health Related Quality of Life
HUI	Health Utilities Index
IES	Impact of Events Scale
Kinship	A socially recognised system of relationships between people in a culture who are held to be biologically related or who are given the status of relatives by marriage, adoption, or other ritual.
MEDLINE	Medical Literature Analysis and Retrieval System Online
NHS	National Health Service
PIC	Paediatric Intensive Care
PICU	Paediatric Intensive Care Unit
PMTS	Pediatric Medical Traumatic Stress
Psychosocial	Interrelation of social factors and individual thought and behaviour.

PTS	Post-traumatic Stress
PTSD	Post-traumatic Stress Disorder
QoL	Quality of Life
Redemption	A sequence from a negative event or circumstance that leads to a demonstrably positive outcome.
Reflexivity	Based on the premise that knowledge and knower are interdependent, reflexivity is an awareness of the influence the researcher has on the research process and outcomes.
Resilience	Ability to recover, cope or adapt in relation to adversity or uncertainty.
Restitution	Where a life event, such as critical illness, is seen as a temporary detour and the focus is placed on returning to normal life.
Social capital	Social resources or assets that are held by an individual, a group, or a community that can facilitate outcomes in relation to status, health and well-being.
SPAN	Short form of Davidson Trauma Scale
UK	United Kingdom
Well-being	An overall condition of an individual or group in relation to their social, economic, psychological, spiritual or health status.

Chapter One
Introduction and overview

1.1 Significance of the study

In childhood and adolescence, critical illness can be caused by a wide variety of diseases and injuries (Advanced Life Support Group, 2011). However, irrespective of cause, it is characterised by a rapid and potentially catastrophic loss of physiological reserve (Aylott, 2010) which can result in significant morbidity or even mortality (Hazinski, 1992). Subsequently, within the developed world, specialist environments, interventions and care have been created to support the vulnerable physical status of critically ill children and adolescents (Downes, 1992; Griffiths and Evans, 2002).

In the UK it is estimated that every year 1 in 1000 children and adolescents will require admission to a Paediatric Intensive Care Unit (PICU) for the treatment of critical illness (Department of Health, 2003). UK statistics identify that utilisation of PICU has increased by 15% over the past 10 years (PICANet, 2014). Approximately 70% of those admitted to the PICU are for the receipt of unplanned or emergency critical care (PICANet, 2014). International studies indicate that up to two-thirds of children admitted have a pre-existing health condition (Gemke, Bonsel and van Vught, 1995; Jayashree, Singhi and Malhi, 2003).

Critically ill children and adolescents are exposed to continuous monitoring, and multiple interventions and therapies, to support their compromised physiological status. On average, children and adolescents receive 89 invasive procedures per stay (Rennick, Johnston, Dougherty et al., 2002). These can include: intubation and mechanical ventilation; endotracheal suctioning; intravenous and central line cannulation; chest tube placement; and urinary catheter insertion. In addition, children may receive numerous infusions of medications which can have disturbing side effects such as hallucinations and delirium (Colville, 2005). Sedative medications are extensively used and are reported to suppress the child's awareness as well as ordinary cycles of thirst, hunger and emotions (Carnevale, 1997). The PICU is identified as an adverse environment due to continuous light

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and noise from large numbers of staff as well as monitoring equipment and machinery (Morrison, Haas, Shaffner et al., 2003; Mullen and Pate, 2006). Noise levels are reported to be as much as eight times higher than levels recommended for hospitals (40dB) by the World Health Organisation (Milette and Carnevale, 2003). PICU hospitalisation has been reported to be a period of crisis for a family (Atkins, Colville and John, 2012). The experience can incite considerable levels of fear and anxiety with regard to any potential losses that may be faced, such as brain damage, disfigurement, or death (Colville, 2005).

Due to significant medical and technological developments, mortality from critical illness is rare with the majority of children admitted to the PICU ($\geq$96%) being discharged alive (PICANet, 2014). Despite high levels of survival, there remains high rates of morbidities in children and their families following critical illness. Physical impairment and residual health problems have been reported for survivors in the longer term. Psychological impact has been reported for survivors and families (Shudy, de Almeida, Ly et al., 2006; Rennick and Rashotte, 2009) although this has been predominantly in the immediate to short term following the critical illness event. Research that has attempted to explore longer-term experiences of PIC survivors is dominated by decontextualized and pathologised constructions of survival, or adult voices that appear to impede child and adolescent accounts and constructs.

Collectively, there is a paucity of published literature providing a comprehensive and contextualised understanding of how PIC survivors construct and experience psychosocial well-being in the long-term (Rennick and Rashotte, 2009), thus justifying further research within this area. Given the paucity of primary research in this field, this study explored how long-term psychosocial well-being was constructed and experienced through the stories of childhood survivors and their significant others, within the context of their lives.

1.2   Personal reflections and ambitions for this inquiry

A number of personal and professional ambitions inspired and guided this study and are expounded throughout this thesis. I embarked on this research as an experienced PIC nurse and an enthusiastic, but neophyte, researcher. Having worked within PIC for seven years, I had developed experiential insights and skills

in caring for the most critically ill and injured children, adolescents and their families. The vast majority of these children survived, although many suffered physical impairment or co-morbidities. Despite not achieving 'full recovery', these children were perceived by professionals and parents as a success, as death was avoided.

However, I contemplated what happened to these children and their families post-PICU discharge and whether residual scars were just physical. This, in turn, provoked contemplation of whether survival from childhood critical illness was a crude measure of effectiveness. Certainly it appeared incongruent with contemporary healthcare policies, such as Equity and Excellence (Department of Health, 2010), that focus on the importance of monitoring quality, efficacy, and resource utilisation. I appeared not alone in this mind-set as, within the literature, mortality appeared no longer the only outcome of interest (Berenholtz, Dorman, Ngo et al., 2002; Warwick, 2012). However, further engagement with the literature and national outcome data revealed that quality assessment of this patient group was poor (Taylor and Butt, 2000) with non-physical longer-term outcomes unreported. In addition to minimal understanding of long-term experience of PIC survival, inequality in services provided to support and rehabilitate these children was evident. Despite residual adversities, such as physical impairment and post-traumatic stress, being reported to manifest extensively post-PICU discharge, no national guidance or services currently exist for PIC survivors and their families. This is in contrast to services for adult critical illness survivors as both national guidance and infrastructure to support and rehabilitate exist (National Institute for Health and Care Excellence, 2009, 2014). Therefore, I aspired to illuminate insights into the experiences of PIC survivors in the long-term that could inform clinical practice and the services provided.

1.3   Clarification of terms

Within this thesis, a number of concepts or terms are utilised that have multiple uses, definitions, and operational meanings within the literature. To ensure clarity and consistency to the reader, I will briefly define how these key terms have been used in this document.

Children and adolescents

Children, childhood and adolescence have been reported to be concepts that are constructed, developed, and perceived according to biological, societal and cultural factors. Frønes (1993) clearly articulates this point by stating,

> *'There is not one childhood, but many, formed at the intersection of different cultural, social and economic systems, natural and man-made physical environments.'*　　　*(cited in James and Prout, 1997, p. xiii)*

However, for the purposes of this study, children and adolescents will be defined by chronological age. Therefore, chronologically, childhood commences at the age of three years, when infancy ends (Leman, Bremner, Parke et al., 2012). Childhood is reported to end at 12 years when adolescence begins. The upper age in which adolescence ends ranges in the literature from 18 to 25 years (Bronstein and Montgomery, 2011). However, the UN Convention on the Rights of the Child specifies that childhood ends and adulthood begins at the age of 18 (United Nations, 1989). Therefore, within the context of this thesis, childhood, children and adolescents will refer to those aged between three and 18 years old, unless otherwise stated.

Survival and survivor

Survival, and associated terminology such as survivorship, has been recognised within the literature as having a myriad of definitions and connotations (Doyle, 2008; Peck, 2008). However, within the context of this thesis, the term 'survival' is used in its most literal sense as meaning to avoid death. Since critical illness is characterised as an acute life-threatening episode, survival is used to describe individuals who live beyond this event, and are therefore termed a 'survivor'.

Paediatric Intensive Care and the Paediatric Intensive Care Unit

Paediatric Intensive Care (PIC) is a term used to define the care received whilst the child or adolescent is critically ill but is not determined by the environment in which care is delivered. In contrast, the Paediatric Intensive Care Unit (PICU) is the environment in which the specialist PIC is delivered. These units house equipment and designated teams of staff who are trained in providing intensive

care to critically ill and injured infants, children and adolescents (Padiatric Intensive Care Society, 2010).

Parent and parental responsibility

In this thesis the terms 'parent', 'carer' or 'guardian' align to the definition outlined in the Education Act (1996, Section 576). This includes: all natural parents, irrespective of marital status; any person who, although not a natural parent, has parental responsibility for a child; any person who, although not a natural parent, has care of a child.

The Children Act (1989) definition of 'parental responsibility' will be used which identifies those with the responsibility and authority to a child and their property is held: automatically to mothers (married or unmarried) and fathers who were married to the mother when the child was born; unmarried fathers who jointly register the birth of the child with the mother; by completing a parental responsibility agreement; or by obtaining an adoption order from the court.

1.4   Thesis structure

To facilitate the reader's orientation of this thesis, the structure and content will be briefly summarised.

Chapter Two is divided into two parts. The first presents a narrative review of existing literature that has explored experiences and outcomes of surviving childhood critical illness, in the short and longer terms. Insights and gaps from this literature will be expounded, providing a rationale for a systematic review that exclusively synthesises child and adolescent PIC survivor reports of their long-term psychological and social experiences and outcomes. The second part presents a qualitative systematic review and thematic synthesis. Review findings will be discussed which will clarify the knowledge gaps in the field. The chapter concludes with a robust rationale for this study.

Chapter Three outlines the methodology and methods used in this study. As children and adolescents were central to this inquiry, the chapter begins with a discussion of ethical research with children and how they were situated in this study. The philosophical and methodological underpinnings are then outlined. The utilisation of a longitudinal, qualitative, multiple-case study approach is

justified. Methods utilised for data collection (interviews and art-based approaches), analytical techniques, and quality assurance processes used are outlined. Personal reflections pertaining to my own role and positioning as the researcher in this study are expounded.

Chapter Four serves to contextualise the findings presented in the subsequent trilogy of chapters (five, six and seven). An overview of the recruitment, demographics and composition of participants in each case study is presented. A summary of the types of data and times at which they were collected is outlined.

Chapters Five to Seven present the study findings in a sequential manner, that mimics the analytical process (abductive to inductive) employed, and builds on the previous chapters to provide novel insights into the phenomenon. **Chapter Five** presents the vignettes and re-storied accounts of nine PIC survivors, who were central to this study. Using narrative psychological analysis, the story of each survivor is told, eliciting their key life chapters, imagery, events and genres. This chapter provides in-depth, unique and contextualised insights in the nine survivors' self and social worlds. **Chapter Six** expounds the analysis from within each of the nine case studies. A synopsis of each of the 23 'significant others' selected by PIC survivors to form their case is presented, followed by a summary of their stories. These accounts are compared against the stories of PIC survivors (presented in Chapter Five) to illuminate convergent and divergent imagery, themes and genres within each case. **Chapter Seven** presents the findings from the cross-case analysis, which provides understanding of the phenomenon (or *quintain*[1]) across instances and contexts. An aggregation of findings from the nine PIC survivors (Chapter Five) and the whole-cases (Chapter Six) is presented. Collectively, PIC survivors' accounts allude to psychosocial well-being as constructed and experienced in relation to four main themes: disrupted life story; exposure to death and dying; dealing with different social worlds and identities; and getting on with life. When aggregating the case findings as a whole, four dominant themes emerged: dynamic identities, transitioning and transforming selves; contemplation of death and evolving emotional and psychological well-being; biographical uncertainties and identity disturbances; and hope, time and professed resilience. From these findings, collective assertions are made in

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1 The individual cases share a common characteristic. They may be members of a group or examples of a phenomenon. This group or category is called the quintain (Stake, 2006)

relation to how long-term psychosocial well-being is constructed and experienced by PIC survivors within the context of their lives.

The final chapter, **Chapter Eight**, discusses the core study findings with reference to existing research and theories. Reflexive and methodological insights in relation to situating the study, the researcher and participants are expounded. Implications for clinical practice, policy and future research are presented.

Chapter Two

Literature Review: Surviving critical illness in childhood[2]

2.1   Introduction

This chapter situates the study within the existing empirical and theoretical literature. A funnel structure (Figure 1) has been adopted in order to guide the reader through the existing literature towards a definitive study rationale.
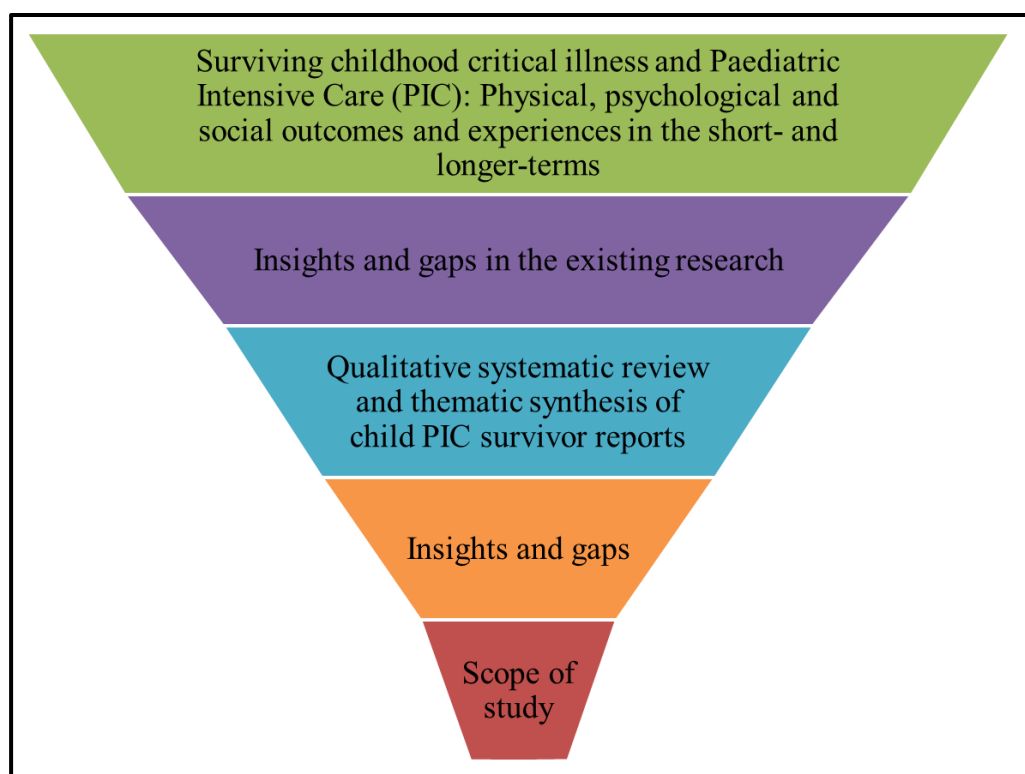
Figure 1: Funnel structure of Chapter Two

The first part of this chapter presents a narrative review of existing literature that provides an overview of the physical, psychological and social experiences and impacts on children and adolescents following critical illness. This literature will be explored in relation to how outcomes manifest from the time since critical

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[2] Part of this chapter has been published in: Manning, J. C., Hemingway, P., and Redsell, S. A. (2014). Protocol for a longitudinal qualitative study: survivors of childhood critical illness exploring long-term psychosocial well-being and needs—The SCETCH Project. **BMJ Open** 4(1); and Manning, J.C., Hemingway, P., and Redsell, S.A. (2014) Long-term psychosocial impact reported by childhood critical illness survivors: a systematic review. **Nursing in Critical Care**, 19: pp. 145-156.

illness. As defined by Friedrich, Wilson and Chant (2006) outcomes and impacts will be divided into the (1) immediate-short term (<six months) and (2) longer-term (>six months). Mechanisms that have been proposed to explain observed experiences and impact will be reviewed. The section concludes by summarising the gaps within the existing body of literature, providing rationales for a qualitative systematic review and a platform to situate this empirical study.

The second part presents a qualitative systematic review and thematic synthesis of published literature that has explored long-term psychological and social experiences, impacts and needs as reported by child and adolescent PIC survivors. Novel findings from this systematic review will be discussed which will further illuminate the knowledge gaps in the field.

This chapter will conclude with a robust rationale for a qualitative empirical study being conducted that explores childhood survivors' long-term psychosocial well-being within the context of their lives.

2.2 Surviving childhood critical illness: a narrative review

2.2.1 Literature scope and search strategy

The purpose of this narrative review was to explore the short (<6 months) and longer-term (>6 months) physical, psychological and social experience and impact of surviving critical illness in childhood. A broad search of electronic databases (CINAHL, MEDLINE, EMBASE, PsychINFO, ASSIA and Web of Science) was conducted initially in April 2011 and updated in December 2014. Search terms[3] included:

- Child* OR p#ediatric OR adolescen*

- Intensive care OR critical care

- Physical OR psychological OR psychosocial OR social OR emotion* OR behavio#r* OR impact OR effect* OR experience* OR outcome*

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3 '*' and '#' indicate the use of truncations to search for multiple terms that begin with a specific prefix or have alternative spellings.

• Severe OR critical OR serious OR life threatening AND admission*OR illness* OR injur#* OR episode*OR event*OR trauma*

Searches were limited to 1955 onwards, as this was when the first Paediatric Intensive Care Unit (PICU) was established (Morton, 1997)[4]. Lists of references from relevant papers were also searched to identify articles and grey literature. Alerts were set up with selected databases and journals, and ongoing dialogues were conducted with international experts in the field.

2.2.2 Immediate to short-term (≤ 6 months) outcomes of child and adolescent critical illness survivors

Physical functioning and health-related quality of life

In the short term, physical functioning and health-related quality of life (HRQoL) have been reported to be adversely affected in the majority of PIC survivors (Morrison, Gillis, O'Connell et al., 2002; Jones, Rantell, Stevens et al., 2006; Knoester, Bronner and Bos, 2008a; Knoester, Bronner, Bos et al., 2008b). Residual physical sequalae have been attributed to the physiological mechanisms of critical illness as well as exposure to critical care interventions.

In a study of previously healthy children, less than a third of survivors were assessed as being in full health at three months post-PICU discharge, with respiratory and neurological problems being the most prevalent morbidities (Knoester et al., 2008a). In relation to HRQoL, a number of domains have been reported to be affected at three and six months post-PICU discharge. A Dutch prospective cohort study of previously healthy children (n=142) collected data in relation to HRQoL using validated measures[5] at three months post-PICU discharge (Knoester et al., 2008b). Functional impairment was identified from 31 child and 55 parent reports, with lung problems most prevalent in survivors aged one to six years, and impaired motor functioning in survivors aged six to 15 years (Knoester et al., 2008b). A UK survey of 1455 PIC survivors by Jones et al. (2006)

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[4] Called the 'pediatric emergency ward' by Dr Goran Haglund, Sweden. The first UK PICU was established in 1965.

[5] Parent reported measures included: TNO-AZL Preschool Children QoL Questionnaire, TAPQOL-PF; and TNO-AZL Children's QoL Questionnaire Parent Form, TACQOL-PF. Child reported measures: TNO-AZL Children's QoL; Questionnaire Child Form, TACQOL-CF.

measured HRQoL using a parent-completed survey (Health Utilities Index 2). Results found only 27.3% of survivors were in full health. Most children were reported to experience some residual morbidity, with sensation impairment most common (42.9%) (Jones et al., 2006).

Recall and memories of PIC experience

Children's recall of their PIC experience has been investigated in both the immediate (Vanek, 1979; Carnevale and Gaudreault, 2013) and short-term (Playfor, Thomas and Choonara, 2000; Rennick, Stack, Ghosh et al., 2011a). Between 58-100% of survivors recall their PIC experience, with recollections predominantly relating to their admission, the PICU environment, and medical interventions (Vanek, 1979; Playfor et al., 2000; Board, 2005). Memories have been categorised within the literature as positive, neutral or negative, with positive or neutral memories infrequently reported. However, in studies that have reported positive or neutral memories, survivors describe the PICU as a comfortable, relaxed or friendly atmosphere, with television and videos being particularly valued (Playfor et al., 2000; Carnevale and Gaudreault, 2013).

Negative memories have been categorised in 15% - 50% of PIC survivor accounts (Karande, Kelkar and Kulkarni, 2005; Rennick and Rashotte, 2009). This variation could be attributed to differences in the time of data collection or methods used for obtaining and categorising memories. However, negative memories have been associated with traumatic aspects of the PIC hospitalisation. Conversations with child and adolescent survivors prior to transfer from PICU identified 'discomforts' associated with pain, invasive interventions, and missing significant people (Carnevale and Gaudreault, 2013). Up to five days post-PICU discharge, 50% of PIC survivors have been reported to recall at least one negative experience, with negative recollections relating to being unable to eat or move, medical procedures, and the death of other children (Karande et al., 2005).

The majority of PIC survivor memories have been defined as factual. However, at three months post-PICU, 32% were found to have delusional memories (Colville, Kerry and Pierce, 2008). Early researchers in the field attributed survivors' distorted memories to children's limited cognitive ability (Barnes, 1975; Vanek, 1979). However, contemporary explanation identifies delirium as influential

(Colville et al., 2008). Delirium is defined as an acutely confused state relating to an individual's consciousness and cognitive function (National Institute for Health and Care Excellence, 2010). Delirium has been reported to have a cumulative incidence of 5% in survivors post-PICU discharge, with a higher incidence in males and older children (Schieveld, Leroy, van Os et al., 2007).

Emotional response

Emotional responses in PIC survivors have been investigated up to six months post-PICU discharge, with negative emotions most frequently reported (Playfor et al., 2000; Karande et al., 2005; Rennick, McHarg, Dell'Api et al., 2008). The origin and prevalence of emotional responses vary amongst studies. Recall of experience has been found to provoke negative emotions (Barnes, 1975; Colville, 2008). Adverse memories have been associated with fears and anxieties due to perceived dangers of being on PICU and the expectation of pain (Colville et al., 2008). The prevalence of increased levels of fears ranges from 13% to 50% (Playfor et al., 2000; Rennick et al., 2002; Rennick, Morin, Kim et al., 2004). This variation could be attributed to the time of data collection as levels of fear have been reported to decrease over time (Rennick et al., 2002). Younger children and children exposed to higher numbers of invasive procedures have been identified as having greater levels of fear post-PICU discharge (Rennick et al., 2002; Rennick et al., 2008). Furthermore, separation from parents and readmission to hospital have been associated with heightened levels of anxiety (Rennick et al., 2008; Rennick, Johnston, Lambert et al., 2011b). Other emotional responses such as anger and irritation are found to manifest up to three months post-PICU discharge (Knoester et al., 2008b).

Despite survivors being able to recall traumatic memories, these have been identified in some studies as not directly associated with anxieties or fears post-PICU discharge. Low or normal levels of anxiety have been reported for PIC survivors who can recall adverse memories relating to interventions and procedures (Board, 2005). Anxieties have been identified in survivors with amnesia of their PIC experience, demonstrating that negative emotional responses are not dependent on recall (Carnevale, 1997; Board, 2005). This is attributed to psychological harm resulting from accumulated periods of partial or distorted awareness (Carnevale and Gaudreault, 2013). In contrast, PICU admission can

also result in positive emotions with one study identifying 88% of survivors as having positive experiences, attributed to the environment and staff (Karande et al., 2005).

Survivor stress has been associated with negative emotional responses. Stressors reported by survivors at 48 hours post-PICU discharge have been linked to exposure to invasive procedures and the critical care environment (Tichy, Braam, Meyer et al., 1988). Subsequently, the PIC experience has been recognised as presenting a variety of disease-, treatment-, and environment-related stressors that may place children at risk of stress and post-traumatic stress (PTS) symptoms (Colville, 2008; Rennick and Rashotte, 2009). As outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), symptoms associated with traumatic events can include: intrusive thoughts; persistent avoidance of stimuli; negative alterations in cognitions and mood; and alterations in arousal and reactivity (American Psychiatric Association, 2013). Up to three months following discharge, stress and associated symptoms have been reported to manifest in as many as one-third of PIC survivors (Bronner, Knoester, Bos et al., 2008b; Rennick and Rashotte, 2009). PIC survivors are recognised as having significantly more PTS symptoms when compared to a control cohort of non-PICU hospitalised children (Rennick et al., 2004).

Self-esteem and control

Self-esteem and perceived level of control have been reported to be negatively affected up to six months post-PICU discharge. Critical illness has been reported to involve a qualitatively diverse experience, which renders the child or adolescent unable to rally against the adversity to which it is exposed (Carnevale, 1997). Child survivors are reported to experience changes in relation to their behaviour, memory, attention span, self-esteem and self-confidence (Carnevale, 1997; Rennick et al., 2002; 2008). Elevated levels of avoidance, low self-esteem and depression have been reported in PIC survivors one month post-PICU discharge (Muranjan et al., 2008) with younger children and those more severely ill having lower perceived levels of control up to six months post-PICU discharge (Rennick et al., 2002).

Social and family functioning

Following critical illness, PIC survivors have been reported to experience increased time off school, (Carnevale, 1997; Rees, Gledhill, Garralda et al., 2004) bullying, (Carnevale, 1997) and many outpatient and inpatient visits (Carnevale, 1997; Rees et al., 2004). The social functioning domain of Quality of Life (QoL) has been reported to be negatively affected at three months post-PICU discharge (Knoester et al., 2008b).

Similarly for the parents and siblings, having a child survive PIC has been reported to place an enormous physical, psychological, emotional and social burden, due to evolving responsibilities and roles (Shudy et al., 2006). As such, parents have been reported to experience high levels of anxiety and PTSD symptoms post-PICU discharge. Bronner, Peek, Knoester et al. (2010) explored PTSD in parents after emergency PICU admission of their child. Parents (n=190) completed the Self-Rating Scale for PTSD (SRS-PTSD) three months post-PICU discharge. In total, 30.3% of parents met criteria for subclinical PTSD and 12.6% for clinical PTSD at three months. Furthermore, a postal survey of 161 parents, at an average of four-month post-PICU discharge, found 21% of respondents met symptom criteria for PTSD (Balluffi, Kassam-Adams, Kazak et al., 2004). Elevated rates of PTSD were associated with those who experienced an unexpected admission of their child, the fear their child might die, and the occurrence of another hospital admission. A higher prevalence was reported in mothers compared with fathers (Shudy et al., 2006), although this finding could be attributed to the prevalence of maternal and the paucity of paternal reports within the literature.

Explanatory mechanism of short-term impact

Much of the literature reviewed in this section has focused on the trauma and negative impact (such as stress and associated symptoms) of surviving PIC in the short-term. Subsequently, trauma theory is the dominant explanatory framework in which this research has been developed or tested (Atkins et al., 2012). Trauma has been defined as resulting from a sudden, unpredictable, life-threatening event that is out of the ordinary (Keane, Marshall and Taft, 2006) and provokes threats to physical and psychosocial integrity which can profoundly affect an individual's health, mental and social well-being (Kira, Lewandowski, Templin et al., 2008).

Evident from Figure 2, exposure to trauma emanates from the PICU environment, critical illness disease processes, and subsequent experiences. This is defined by the framework of Pediatric Medical Traumatic Stress (PMTS) as 'a constellation of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences' (Kazak and Simms, 1996, p.343).
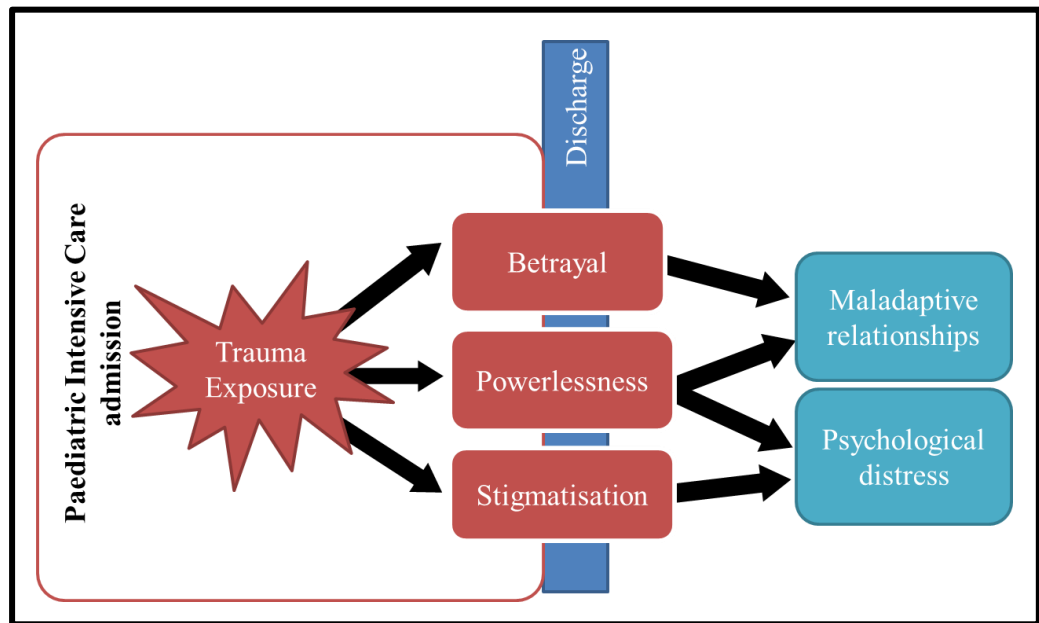
Figure 2: Conceptual schema of trauma theory as applied to PICU survival[6]

From this trauma, psychological functioning is affected through inciting powerlessness and betrayal (Finkelhor and Browne, 1985). Atkins et al. (2012) identify that, for PIC admission, powerlessness would appear to be particularly poignant as children are vulnerable. Furthermore, if parents are perceived not to protect children against traumatic experiences whilst on PICU, then they may also feel betrayed. Glaser (1991) later added further components to this model, including the recognition of extreme fear and isolation. Initially, these stress responses are a normal and adaptive reaction to a life-threatening medical event. However, some survivors have been reported to demonstrate pathological and chronic stress responses over time attributed to maladaptation and not coping (Kazak and Simms, 1996).

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[6] Informed from readings by Finkelhor and Browne (1985) , Glaser (1991) , Stevenson (1999), and Salmon and Bryant (2002).

Theoretical propositions are consistently reported in findings of studies exploring the short-term impact as PIC survivors exposed to greater traumas are recognised as having worse outcomes. Specifically, PIC survivors exposed to: an emergency PICU admission; delusional memories and hallucinations; higher numbers of invasive procedures; or are of a young age have greater levels of fear and stress symptoms in the short term (Rennick et al., 2002; Colville, 2008; Rennick et al., 2008). Furthermore, readmission to hospital and being separated from their parents have also been associated with heightened levels of anxiety (Rennick et al., 2008; Rennick et al., 2011b). Elevated levels of avoidance, low self-esteem and depression have also been reported up to six months post-PICU discharge in young PIC survivors and those more severely ill (Rennick et al., 2002).

However, trauma theory does not provide explanations for all the findings related to PIC experiences in the short-term. Trauma experienced by PIC survivors is not necessarily confined to a one-time occurrence and exposure can take a number of forms. Trauma theory, or at least how it has been conceptualised in relation to PIC survival, is linear and uni-directional. This may be due to an oversimplification as the theory portrays survivors' response to PIC exposure as homogenised and constrained by developmental level.

Summary of short-term experiences and impact

Collectively, existing literature has explored the experiences and outcomes of PIC survivors in the immediate to short term using a range of research approaches and designs. From both qualitative and quantitative findings, time spent unwell in PICU has been reported to result in a range of psychological manifestations in child and adolescent survivors that can include negative thoughts and emotions, decreased levels of self-esteem and reduced perceptions of control. Nightmares and hallucinations have been reported to manifest for a number of months post PICU discharge (Carnevale, 1997; Playfor et al., 2000). Up to six months following critical illness, a range of negative physical, psychological and social outcomes have been reported for the child and their family. These findings have been established through a range of PIC survivor and parental reports, providing a comprehensive understanding of experiences and outcomes.

2.2.3 Longer-term (≥6 months) outcome and impact of child and adolescent critical illness survivors

Physical functioning and HRQoL

Physical functioning and HRQoL have been investigated in survivors up to 16 years post-PICU discharge (Buysse, Raat, Hazelzet et al., 2008; Buysse, Oranje, Zuidema et al., 2009). Despite mortality from childhood critical illness decreasing, the literature identifies that morbidities have increased, with only approximately one-third of PIC survivors in full health at a year post-discharge (Morrison et al., 2002; Jayashree et al., 2003; Buysse, Raat, Hazelzet et al., 2007). This is further supported by findings from two prospective cohort studies conducted in the same Australian PICU 23 years apart (Butt, Shann, Tibballs et al., 1990; Namachivayam, Shann, Shekerdemian et al., 2010). Study findings identify that, at one year post-PICU discharge, despite the prevalence of death decreasing from 14.3% to 5.4%[7], the prevalence of moderate/severe disability increased from 8.4% to 17.9% (Namachivayam et al., 2010). However, studies have also identified that 60–80% of PIC survivors have good HRQoL at greater than six months post-PICU discharge (Morrison et al., 2002; Jayashree et al., 2003; Taylor, Butt and Ciardulli, 2003; Buysse et al., 2007).

Survivors admitted to PICU with certain conditions have been identified as particularly susceptible to physical sequalae or impaired HRQoL in the longer term. For example, a Dutch study has reported that nearly half of meningococcal sepsis survivors experienced skin scarring and one-third experienced long-term neurological impairment (Buysse et al., 2009). PIC survivors with malignancies have been reported to have the worst HRQoL compared with other disease groups (Morrison et al., 2002). Jayashree et al. (2003) found that, from a general cohort of children admitted to PICU, when compared to their pre-morbid state, those with neurological illness had the greatest deterioration in overall health status. The majority of these morbidities have been causally attributed to the pathological process of underlying disease rendering the child critically ill. Furthermore, impairments have been identified that particularly relate to cognition, mobility, pain and sensation, and self-care (Gemke et al., 1995; Jayashree et al., 2003;

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[7] Percentage calculated by Namachivayam et al. (2010) and assumes that no child died after being lost to follow up.

Taylor et al., 2003). Factors associated with poor HRQoL include increased severity of illness (Morrison et al., 2002) and increased length of PIC stay (Morrison et al., 2002).

Stress symptoms

Post-traumatic stress disorder (PTSD) and associated symptoms have been reported to manifest in survivors up to twelve months post-PICU admission (Rennick and Rashotte, 2009). The PTSD diagnostic criteria stipulate that exposure to the trauma must result from: directly experiencing; witnessing in person; learning that it occurred to a close family member or friend; or being exposed to repeated or extreme exposure details of the traumatic event (American Psychiatric Association, 2013).

Existing research recognises that PIC survivors are at increased risk of developing PTSD symptoms due to the stress of the critical illness event and interventions (Judge, Nadel, Vergnaud et al., 2002; Rees et al., 2004). Specifically, a number of factors have been associated with increased stress levels post-PICU discharge that include: exposure to invasive procedures (Rennick et al., 2004), greater illness severity (Judge et al., 2002; Bronner, Knoester, Bos et al., 2008a), PTSD in the shorter-term (Colville, 2008) and a younger age at PICU admission (Vermunt, Buysse, Joosten et al., 2008). However, prevalence varies, with PTSD symptoms reported to manifest in the long term in 34% to 68% of PIC survivors (Judge et al., 2002; Bronner et al., 2008a). In conjunction with reported variance, inconsistencies exist within the literature in relation to explanations of how PTSD symptoms manifests over time, and whether symptoms are residual or transient (Rees et al., 2004; Rennick et al., 2004; Bronner et al., 2008a; Board and Dai, 2010). Findings from a recent UK single centre cohort study (Colville and Pierce, 2012) confirm this inconsistency. The researchers assessed PTSD symptoms in 66 PIC survivors (aged seven-17 years) at three and twelve months post-PICU discharge using the Children's Revised Impact of Event Scale (CRIES-8). Findings identified little difference in the proportion of PIC survivors scoring clinically significant PTS symptoms[8] between the two time points. However, at 12 months post-PICU discharge, approximately half of the cases were newly

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[8] Classified as a total score of 17 or more.

manifesting, when compared to three months (Colville and Pierce, 2012). This suggests there may be other factors prior to or following critical illness that might be influential to psychological outcomes in the long-term.

Quality of Life, social and family functioning

The long-term impact of surviving PIC on QoL and social functioning has been explored within the international literature. A systematic review by Rennick and Rashotte (2009) found QoL, assessed using survey methods, is negatively affected in survivors up to six years post-PICU discharge. In contrast, Morrison et al. (2002) identified that, despite the majority of participants having a good or fair QoL, ongoing emotional, social, physical and cognitive problems can manifest, thus indicating that instruments to assess QoL might not be sensitive enough to capture nuanced outcomes.

Qualitative approaches have been applied to explore psychological and social functioning in the longer term. A Canadian single centre study explored survivors (n=20, aged 2 weeks to 16 years) and their families during their PICU admission and up to five years post-PICU discharge using hermeneutic phenomenology (Schultz and Carnevale, 1996; Carnevale, 1997). Researcher field-notes and interviews identified long-term survival as an overwhelming and qualitatively-diverse experience. Changes in relation to PIC survivors' physical and behavioural status appeared to negatively impact on their social standing due to increased time off school and exposure to bullying (Carnevale, 1997). This study illuminates the complexity and interplay between facets of individual and social worlds, through the application of a longitudinal approach which appears suitable for exploring a complex phenomenon. However, a number of limitations are evident. In the reporting of his study, no sampling approach is identified nor does Carnevale outline the characteristics of the sample, thus limiting the transferability of the findings. It is unclear where the PIC survivors' experiences are located amongst the accounts of other people such as the researcher, parents, and health professionals. Furthermore, due to significant advances in PIC service provision since the early 1990's, the relevance of the findings to contemporary survivors within a UK setting is unclear.

A more recent, single centre, qualitative, cross-sectional study conducted in the UK explored experiences of survival from six to eighteen months post-PICU admission using grounded theory (Atkins et al., 2012). From nine families, 13 parents and five PIC survivors (n=5/9, aged five to 17 years) were interviewed at a single time point. Findings identified that PIC survival was a dynamic journey of emotional processing for children and parents, which involved navigating changes in relation to their self-identity and own vulnerabilities. A significant theme that emerged was social recovery which emanated from multiple social adversities within the PICU, such as isolation and disconnection from others. Therefore, initial social processes in survival involved the reconnecting of the social-self with family and the wider social world. This exposed survivors and their families to changes in social identities due to extraneous influences such as disability or changing school. Feelings of isolation also manifested due to uncertainties over whom to discuss their experiences with. However, there are a number of limitations with this study in understanding child and adolescent experiences and impact of surviving critical illness. As recognised by Atkins et al. (2012), the self-selection and homogeneity of the sample in relation to ethnicity could have resulted in findings that do not represent those that did not participate and is ethnocentric. Furthermore, interviews were conducted with just over half of the total number of PIC survivors and it is therefore unclear whether the findings reflect the PIC experiences or have been overwhelmed or diluted with parental accounts. As interviews were conducted at a single time point it is unclear how experiences and impact develop over time.

In relation to the longer-term experiences on the family, psychological and social impacts have been reported. Exploration of long-term stress responses (namely PTSD) in parents following PIC has been the purpose of a number of studies (Balluffi et al., 2004; Melnyk, Alpert-Gillis, Feinstein et al., 2004; Rees et al., 2004; Colville and Gracey, 2006; Bronner et al., 2008b; Colville, 2008; Colville, Cream and Kerry, 2010). Overall, these studies have identified PTSD in 13–27% of parents. Specifically, the study by Rees et al. (2004) found considerable rates of PTSD in parents at six to 12 months post PIC, with one-quarter of parents scoring above the cut-off (The Impact of Event Scale, IES: ≥35/75) for high risk of PTSD. Furthermore, Colville and Gracey (2006) reported from an interview

study with mothers, eight months post PIC-discharge, that 20% demonstrated clinically significant levels of PTSD.

Social functioning has also been explored in relation to families, with positive and negative outcomes of the critical illness experience being documented (Shudy et al., 2006). Enhanced family-child relationships have been reported by parents (Shudy et al., 2006). Tendencies to be more protective of their child, even when they have made a good recovery, has been identified in the literature (Colville et al., 2008; Colville, 2012). The negative impact on marital and domestic partner relationships has also been found in the longer term (Shudy et al., 2006).

Explanatory mechanisms of longer-term impact

Similar to the literature exploring the short-term experiences and impact of PIC survival, trauma theory (outlined on page 14), has also been applied as an explanatory framework for longer-term outcomes. This indicates that the trauma experienced during PICU hospitalisation and the PIC experience result in persistent maladaptive relationships and behaviours, and psychological distress. However, the application of this theory appears limited as reported variance in the residual nature of stress responses is evident. Furthermore, newly emerging stress that manifests some time post-PICU admission (Colville and Pierce, 2013) as well as the outcomes of poly-traumatisation (Gustafsson, Nilsson and Svedin, 2009) are not easily explained by the existing theory. Subsequently, two additional frameworks, the body in pain theory and the biopsychosocial model of recovery, have been reported to provide explanatory understanding of the long-term experiences and impact of PIC survival.

Carnevale (1997; 1999) utilises the body in pain theory proposed by Scarry (1985) as a 'dialectical construal of critical illness in children'(Carnevale, 1997, p.51). This theory argues that pain is the most absolute definer of reality and Scarry conceptualises this as a form of torture. For the person in pain, there is no reality besides pain; if it hurts, it must be real.
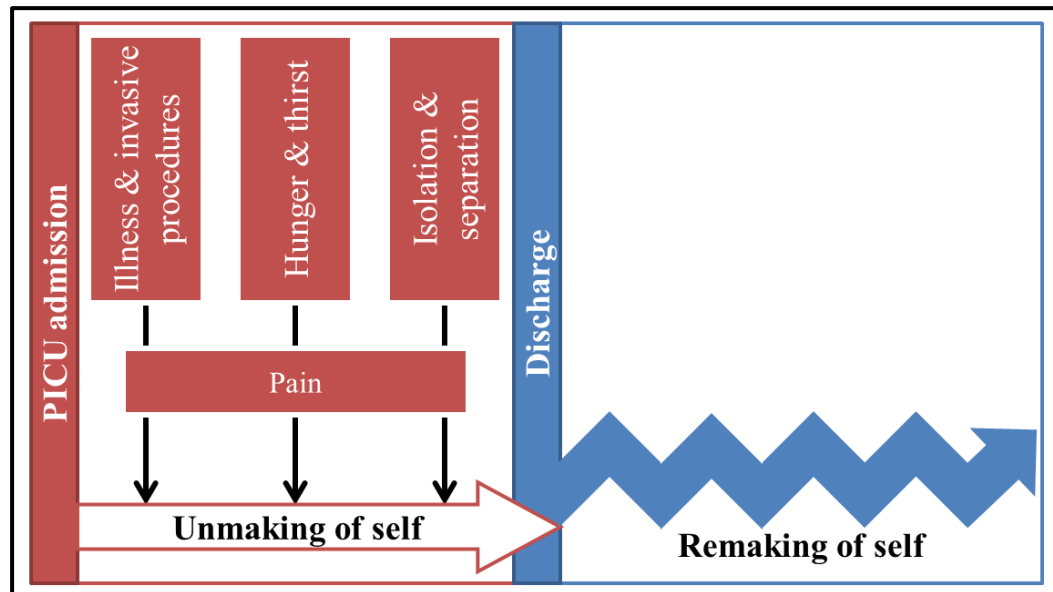
Figure 3: The unmaking and remaking of self in PICU survival[9]

As represented in Figure 3, Carnevale (1997; 1999) conceptualises the critical illness and PICU experience as the 'unmaking' of the child's self. This unmaking is attributed to the iatrogenic harm imposed on the survivor through physical (e.g. illness and invasive procedures), psychological (e.g. stress and fears), and social pains (e.g. isolation and separation). From this state of unmaking, being discharged from PICU allows for the remaking to occur over the following days, weeks and months. Carnevale alludes to 'remaking' as non-linear, shifting between unmaking and remaking, transforming the status of the survivor.

It is evident that the application of this theory has a number of limitations. Firstly, the dimensions, factors or events that are influential in making and unmaking the self during the rehabilitation are not explicated. Carnevale (1997; 1999) proposes that the 're-making' phase occurs when the child is being rehabilitated. However, existing literature identifies residual physical, psychological and social 'pains' such as chronic health impairment or bullying for which this theory does not appear to account. Therefore, it could be argued that this theory provides explanation to experiences whilst survivors are critically ill. However, it neglects ongoing adversity, such as distress, parental stress, disability, and chronic illness. Secondly, for a self to be 'unmade' the child must first have a concept or construct of self. However, it is unclear how this theory is applied in PIC survivors, such as

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[9] Developed from writings by Carnevale (1997, 1999) and Scarry (1985).

infants, who have been identified as having an evolving self-identity (Erikson, 1995).

More recently, Atkins et al. (2012) have proposed an alternative model that conceptualises survival as a pathway of recovery. Using a constructivist grounded theory approach, the researchers use the findings from their study to build on trauma theory and map a pathway of recovery for child survivors and their families. As shown in Figure 4, the theory conceptualises recovery in three pathways in a quest to a new normal (Atkins et al., 2012).
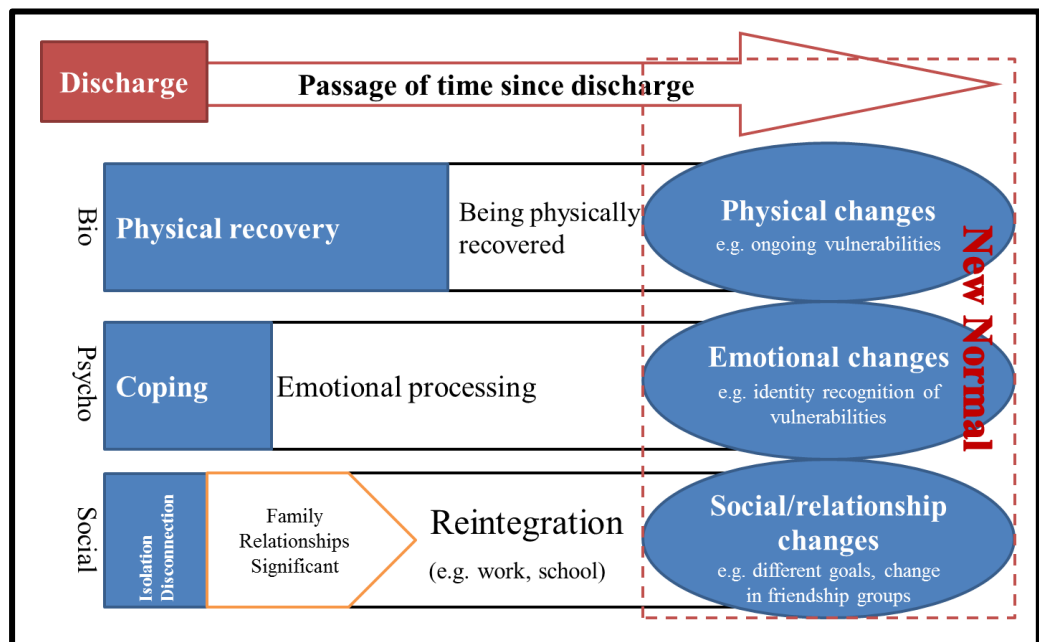
Figure 4: A biopsychosocial model of recovery (Atkins et al., 2012, p. 139)[10]

This model identifies that recovery begins at PICU discharge with the physical pathway central, as Atkins et al. (2012) shows that psychological and social strands remain impaired until physical health, or the new normal, is achieved. From this state of impairment and trauma, reflection on the emotional cost of the PICU admission occurs. Strategies are employed in an attempt to cope with day-to-day life and avoid contemplating some of the adversities endured. Emphasis is placed on achieving the 'normal' which existed pre-PICU admission. This

10 Redrawn and reprinted from Intensive and Critical Care Nursing, 28 (3), Atkins, E., Colville, G., and John, M. A 'biopsychosocial' model for recovery: A grounded theory study of families' journeys after a Paediatric Intensive Care Admission, pp.133-140., Copyright (2012), with permission from Elsevier.

involves a process of contemplation and sharing of stories in order to take control over and clarify experiences (Atkins et al., 2012).

Atkins et al. (2012) describes how the social pathway of recovery is exclusively dependent upon physical recovery. Dependence is imposed due to physical needs. Until physical recovery is perceived as achieved by the family and survivor, social recovery is limited to reintegration within the family environment. This strand of recovery involves exposure to challenges as uncertainties in whom to disclose their experience to exist. Over time, transitions and changes to both survivors' and parents' social identities occur through changes to jobs, education provision and friendship groups.

Collectively, this model does provide a framework to illuminate understanding of observed outcomes and experiences that have been reported in the literature. However, a number of limitations exist. The model was developed from mainly parental accounts (n= 13), with only five PIC survivors interviewed. Although the model represents a pathway of recovery for the family, it is unclear how representative this is of the PIC survivors' journeys. Furthermore, the model does not appear to comprehend the interplay between the bio-, psycho-, and social pathways of recovery. Although Atkins et al. (2012) alludes to some interrelation between self and social worlds, the model is constructed as distinct and linear pathways.

Summary of longer-term experiences and impact

From the existing literature it is evident that, in the longer-term post-PICU discharge, survivors and their families are exposed to residual and newly manifesting physical, psychological and social outcomes.

Physical and functional outcomes have been explored and measured up to 16 years post-PICU discharge in predominantly cohort studies with large samples that reflect the heterogeneity of the PICU populace (Buysse et al., 2008; Buysse et al., 2009). Functional and neurological impairment are the most frequently reported outcomes, and identified to manifest in up to a third of those survivors studied (Jayashree et al., 2003; Taylor et al., 2003; Buysse et al., 2008; Knoester et al., 2008a; Knoester et al., 2008b; Namachivayam et al., 2010).

However, studies that have explored longer-term psychological and social experience and impact vary in their findings. Stress, anxieties and PTSD symptoms have in some studies been reported to decrease over time (Rennick et al., 2002; Board and Dai, 2010), whereas others infer the residual nature of psychological adversity in the longer term (Rees et al., 2004; Colville and Pierce, 2012). Similarly, disparities in QoL have been identified. Impaired QoL has been reported to manifest in 34% of survivors at two years post-PICU discharge (Morrison et al., 2002). Positive experiences and outcomes following PIC have also been reported (Jayashree et al., 2003; Colville and Pierce, 2013) with self-reported QoL being good in the majority of survivors at one-year post-PICU discharge (Colville and Pierce, 2013). Due to a lack of consensus in the reporting of long-term experiences and outcomes, further exploration of the nature and construct of how psychosocial experiences manifest over time is warranted.

A number of studies have indicated disruptions to PIC survivors' lives in the longer term, with increased time off school, bullying, and more outpatient and inpatient visits (Carnevale, 1997; Rees et al., 2004; Board, 2005). Both positive and negative outcomes of the experience have been documented for families of these children (Shudy et al., 2006), but there is a lack of information concerning the interplay between social experiences and other life events. Longitudinal data about survivors' psychological, social and emotional experiences, as well as how these children cope and grow, are absent (Rennick and Rashotte, 2009).

2.2.4   Insights and gaps in the existing literature

This narrative review identifies that surviving critical illness can expose children and their families to a multitude of experiences and outcomes in the short (≤six months) and longer term (≥ six months). However, a number of insights and gaps are evident within this body of research that provides opportunity for further research.

Critical illness in childhood and PICU admission can result in residual functional and health impairment for survivors. However, there is considerable variability in relation to the design of these studies that results in a multiplicity of limitations. Variance includes: the case mix within and between PICUs; low response rates which threaten their validity; different outcome measures used; outcomes are

summarised in very broad terms (good or poor) with no reference to population norms; duration of follow-up varies widely; and infants, who make up a disproportionately high number of PICU admissions, are excluded because of the lack of validated measures for this age group (Colville and Pierce, 2013).

It is evident that the majority of studies have measured impact at pre-determined time points (such as three and 12 months post-PICU discharge) but the researchers neglect to disclose the significance of these. Although administering measures at specific time intervals is convenient for comparison and analysis of data (Shadish, Cook and Campbell, 2002), the specific importance to the child is unclear. This could neglect pertinent information about the child's or young person's experience, emotions and behaviours, as it might not exist at that time point. Therefore, in order to gain understanding of long-term psychosocial experiences of PIC survivors over time, a child participant-directed design should be utilised. This could allow information to be collected at time points, such as transitions of care or important life events which are significant to the child.

UK audit data identify that around 70% of admissions to PICU are children aged three years and under (PICANet, 2013) which infers that the majority of survivors may not have the cognitive developmental capability to self-report[11]. This could contribute to explaining why adult voices appear to exclusively report experience or impact on behalf of childhood survivors (Jayashree et al., 2003; Jones et al., 2006; Small and Melnyk, 2006; Mestrovic, Kardum, Sustic et al., 2007). However, apart from a minority of studies (Carnevale, 1997; Playfor et al., 2000; Rennick et al., 2008; Atkins et al., 2012; Carnevale and Gaudreault, 2013), adult voices continue to dominate reports even for children and adolescents with the cognitive development capabilities. Therefore, in order to understand how survivors experience the impact of surviving critical illness, it is fundamental that approaches used are effective in capturing potentially diverse experiences.

Problematizing survival as the dominant perspective

A further limitation of the existing literature is the investigatory stance adopted. Problematising or pathologising experience and impact of surviving childhood

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[11] For example those who are pre-verbal or who are in their pre-operational stage of development (Piaget, 2001)

critical illness appears the dominant approach used by researchers, resulting in a body of literature that largely focuses on establishing negative aspects of survival. Subsequently, this has led to literature that makes deductive, and in some cases simplistic, claims in relation to the causal inferences of associated variables (such as anxieties, PTSD symptoms, or poor QoL) without exploration of contextual factors or events that could be influential. Collectively, this could have limited understanding of the holistic complexity of surviving childhood critical illness in the long term and, up until recently (see Atkins et al., 2012), hindered the development of theory that comprehends the interplay between the survivor and their social world. Carnevale (2007) recognises this issue in his writing, suggesting that medical research typically implies a set of reductionist assumptions about health phenomena that are commonly unscrutinised. Moreover, social phenomena are reduced to interactions among individuals, limiting the possibility for examining phenomena beyond immediate micro-social levels.

Research in this field appears to align to conventional theories of development, viewing childhood as a dynamic period but also as compartmentalised physical, psychological, cognitive and social units. This has resulted in literature that aligns to researcher-specific interests or professional backgrounds instead of attempting to gain insights into the potentially dynamic and interdependent phenomena.

Medicalised constructs (such as PTSD) appear to be the basis for much of the available literature as these pre-defined symptoms construct survival, and subsequent illness, as a social experience (Hardey, 1998). However, this may not convey the intended personal meanings that childhood survivors of critical illness may have - instead it may inform how their experience is constructed (Holstein and Gubrium, 2012).

An absence of the survivor's voice

In the longer-term (≥6 months), although some studies have attempted to elicit childhood survivor self reports (Rees et al., 2004; Elison, Shears, Nadel et al., 2008; Colville and Pierce, 2013), adult accounts appear to dominate. Parents and health professionals have been used as proxies and have reported experience, impact or outcomes on behalf of childhood survivors (studies include Jayashree et al., 2003; Jones et al., 2006; Small and Melnyk, 2006; Mestrovic et al., 2007),

which could misrepresent the impact on the child (Theunissen, Vogels, Koopman et al., 1998). Eiser and Morse (2001) support this stance in their conclusions from a systematic review that identified disparities between parents' and child ratings of children's HR-QoL. Findings showed greater agreement between child and parent for observable functioning and less for non-observable functioning. Furthermore, children's perceptions of stressors in the PICU have been identified as different from those of parents and nurses (Tichy et al., 1988). Collectively, these suggest that adult reports on behalf of childhood survivors might not reflect children's own experiences. Moreover, the language and manner in which children construct their experiences may not be reflected through the accounts of others due to differing perception and developmental lenses of the world.

Adults appear to have dominated existing literature by imposing specific methods, such as structured interviews and questionnaires (Rennick et al., 2002; Taylor et al., 2003; Rees et al., 2004; Board, 2005), or specific or single time-points to collect information (such as 3 and 9 months : Bronner et al., 2008a; Knoester et al., 2008b) where the relevance to the child or adolescent survivor is unclear. Furthermore, theories or models that attempt to explain observed phenomena have been developed with parental reports. Collectively, this has resulted in the PIC survivors' long-term experiences, views, descriptions, meanings and needs being predominantly unknown, lost or in some cases negated within the literature.

Rationale for further research

Insights from the literature illuminate a number of areas for further empirical inquiry which provide a robust basis to situate this study.

Pathologising or problematising are the dominant approaches in the literature that have been used to investigate survival following childhood critical illness. This focus has produced a body of literature that has identified negative uni-dimensional aspects of existence post-PICU, which has constructed survival for some as problematic and traumatic. Therefore, future research needs to adopt an alternative, non-pathologised stance to provide novel insights.

The longer-term, contextualized experiences and impact of surviving childhood critical illness are unclear, with particular paucity in understanding the interplay

between psychological and social worlds and how this manifests over time. Further research is required, that explores PIC survivors' psychosocial experiences and impact within the context of their lives. As cross-sectional studies have been the dominant design employed, collecting data at specific time points, longitudinal studies are required that provide opportunity to capture the phenomena over time.

The absence of child and adolescent survivor voices within the existing body of literature identifies the need for further research that explores how they experience and construct survival. Furthermore, child-centered approaches and methods that harness previously unheard groups, such as children with neurological impairment, are required.

Well-being as a novel exploratory lens

Changing the stance from a focus of pathologising and problematising the phenomena to a position that is more appreciative and holistic may provide novel insights (Carter, 2006). The notion of well-being has been advocated to provide a platform for an integrated exploration and understanding of experiences as, although it does comprehend deficits and problems, it focuses more on strengths and achievements (Aldgate, 2010). It has long been recognised that psychological well-being is influenced by people's sense of purpose (Frankl, 2006). Furthermore, well-being recognises the interplay of psychological, social, cultural and historical experiences to what was once an entirely physical, science-based medical model (Ereaut and Whiting, 2008). It goes beyond physical health to a more holistic standpoint that challenges mind-body dualism.

Within healthcare, a well-being perspective has been a general movement to challenge and comprehend the multiplicity of factors that influence health beyond disease (Statham and Chase, 2010). In 1948 the World Health Organisation (WHO) used the concept of well-being in their definition of health and since then well-being has become a dominant discourse (Camfield, Streuli and Woodhead, 2008), apparent through much contemporary empirical research, practice guidance and policy (such as NCH The Children's Charity, 2007; Fauth and Thompson, 2009; Statham and Chase, 2010; Ipsos MORI Social Research Unit and Nairn, 2011).

Ereaut and Whiting (2008) identify that well-being is not a familiar term and one that is not recognised or understood by some groups in society, including children. They assert that this is potentially problematic when policy, research and societal aspirations are linked, directly or indirectly, to this concept. However, this ambiguity provides opportunity, as the elasticity of the concept allows for the meaning ascribed to be specific to the audience (Ereaut and Whiting, 2008). Furthermore, Douglas and Ney (1998) argue that much inquiry and analysis of well-being (as well as poverty and welfare) operates devoid of a theory of the person. Therefore, it is fundamental to establish how the person is viewed and situated within the research prior to commencing the inquiry.

Research previously conducted in this field comprehends that childhood is a time of significant change where children and adolescents experience physical, cognitive, and psychosocial development. Theories applied that delineate this period in human development appear to categorise or homogenise children and childhood into discrete developmental stages and levels of competence. Participant inclusion is determined and findings constrained by the developmental expectations of chronological age or disease. This is evident in the exclusion of certain children (such as those with neurological impairment) that, although not explicitly stated by researchers, could sit outside of the developmental sequential ideals.

Rationale for qualitative systematic review

In summary, it is evident that a number of knowledge deficits and methodological limitations exist that collectively limit understanding of long-term psychosocial impact and experiences of surviving childhood critical illness. Existing research is dominated by parents, health professionals, and researchers in defining and reporting psychological impact on behalf of childhood survivors. Subsequently, existing findings may only partially represent the true impact endured by such children and adolescents. Existing research has also predominantly focused on single aspects of impact such as survivor health, emotions, or stress responses. This has resulted in the interplay between the psychological and social worlds being unreported. Collectively this has contributed to a lack of understanding of childhood survivors' self-reported psychological and social impact, experiences, views, perceptions and needs.

Further exploratory work that does not aim to deductively test existing theory is required. As a first step to achieving this, qualitative systematic reviews can offer novel insights into a phenomena which were not apparent from single studies alone, providing a platform to better inform practice, policy, and future research (Barroso, Gallup, Sandelowski et al., 2003; Campbell, Pound, Pope et al., 2003). It is evident from the literature reviewed in this chapter that child and adolescent PIC survivors have been under-represented, through the dominance of adult reports, in studies that have aimed to explore their experiences (Carnevale, 1997; Atkins et al., 2012). Therefore by identifying, extracting and synthesising only child and adolescent reports, a more comprehensive understanding of what is known about their long-term psychological and social experiences can be identified. This will identify approaches and methods that have been used providing direction for future research and justifies the need for a qualitative systematic review.

2.3   Qualitative systematic review and thematic synthesis

The objective of this review was to identify and synthesise qualitative research that explored long-term (post six months from the onset of critical illness event) psychological and/or social impact and needs as reported by child and adolescent survivors of acute life-threatening critical illness. This section will present a summary of the methods, with further detail outlined in the paper by Manning, Hemingway and Redsell (2014). The salient findings from the review will then be discussed and evaluated to demonstrate how they informed this empirical study.

2.3.1   Systematic review methods

The systematic review aimed to assess and synthesise all relevant empirical, qualitative, English language studies using an approach informed by Centre for Reviews and Dissemination (2009) guidance. The thematic synthesis method by Thomas and Harden (2008) was used with a view of enabling the creation of novel explanations or hypotheses.

This review ascribed to a constructivist epistemology where knowledge was seen as being generated in the social world, through the interaction between the researcher and the researched (Bailey, 1997). A realist ontology was adopted that

gains access to an underlying reality through the synthesis of varied and multiple perspectives, which is not apparent on the examination of individual accounts or papers (Walsh and Devane, 2012).

In February 2012 six electronic databases (CINAHL, MEDLINE, PMC, PsychINFO, ASSIA, and Dissertation & Thesis Database) were searched, using single and combination term sets to identify relevant studies (Manning et al., 2014). Hits were exported into EndNote X5™ following removal of duplicate citations. The title and abstract of all articles were screened for eligibility using eight inclusion criteria outlined in Table 1.

Inclusion criteria
1. Qualitative primary research
2. English language
3. Sample studied must include participants that experienced critical illness aged ≤18 years
4. Participants survived an acute life threatening event in childhood requiring critical care
5. Outcomes reported by children, adolescents and young people
6. Outcomes include psychosocial, psychological, social experiences, impact and needs
7. Outcomes reported ≥ 6 months after critical illness
8. Able to extract data from studies with mixed data, such as parent/child reports, critical illness survivors/non-critical illness survivor reports.

Table 1: Inclusion criteria for the selection of studies

Full text copies of studies that satisfied the inclusion criteria were sought. Reference lists were reviewed to identify any relevant studies and key authors were contacted to identify additional data.

2.3.2 Findings: review searches and study selection

As shown in the flow diagram (Figure 5), searches yielded 1307 citations, which were published between 1971 and 2012. Thirty- seven citations were duplicates. Of the 1270 remaining records, 1260 studies were deemed ineligible after screening the title and abstract, resulting in 10 potential studies for inclusion.

1. Study records identified from electronic databases using search strategy
    [CINAHL (n=353), MEDLINE (n=9), PubMed (n=615), PsychINFO (n=326), ASSIA, (n=2),
    Dissertation & Theses (n=2)] **n = 1307**

2. Import studies identified by database search into Endnote and remove duplicates

Duplicates discarded **(n=37)** by:
Author/Year/Title/Source n= 28
Author/Year/Title n= 5
Author/ Title n=1
Author/ Date n=3

Non-duplicates **n = 1270**

3. Records screened by *JM* from title and abstract to assess if meets inclusion criteria.

Failed to meet inclusion criteria
n= 1260
- n=760 : Not a qualitative empirical study
- n=489 : Participants did not survive acute life threatening event requiring critical care
- n=5 : Majority of study sample not aged ≤18 years
- n=4 : Long term outcomes defined by ≥ 6 months after critical illness not reported
- n= 1: Outcomes not reported by children/adolescents
- n=1 : Single case study

Meets criteria **n = 2**

Unclear from title and abstract if meets all inclusion criteria **n = 8**

6. Obtain full text hard copies

4. Full text hard copies obtained

5. Records re-screened by *JM* to assess if meet inclusion criteria

Failed to meet inclusion criteria
n= 7
- n=3: Not a qualitative empirical study
- n=2: Unable to extract child/adolescent data
- n= 1: Outcomes not reported by children/adolescents
- n=1: Long term outcomes defined by ≥ 6 months after critical illness not reported

n = 2

Meets criteria **n = 1**

7. Conduct lateral search of reference lists of studies. Obtain full text hard copies and include in next stage if meets inclusion criteria.

n = 3

8. Records re-screened independently by *JM* and *SR* or *PH* to assess if meet inclusion criteria

Failed to meet all criteria **n= 0**

Meets criteria **n = 3**

9. Selected for assessment of methodological quality

Figure 5: Flowchart of systematic review study selection[12]

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[12] Key: JM- Joseph Manning, SR- Sarah Redsell, PH- Pippa Hemingway

Screening of the full text reports resulted in seven papers being excluded with reasons provided in Table 2.

Authors (Year)	Paper title	Reason for exclusion
Carnevale (1997)	The experience of critically ill children: narratives of unmaking.	• Unable to extract child reported data from those of others
Noyes (2000)	'Ventilator-dependent' children who spend prolonged periods of time in intensive care units when they no longer have a medical need or want to be there.	• Unable to extract data from children who experienced critical illness from those of other participants
Rennick et al. (2002)	Children's Psychological Responses After Critical Illness and Exposure to Invasive Technology	• Not a qualitative empirical study • Data only collected up to 6 months post critical illness
Orne (1995)	The meaning of survival: the early aftermath of a near-death experience	• Outcomes not reported by children, adolescents and young people
Sarvey (2008)	Living with a machine: the experience of the child who is ventilator dependent.	• Time since critical illness not reported. • Evidence that only one participant survived an acute life threatening critical illness/injury requiring critical care. • Unable to extract data from children who experienced critical illness from those of other participants.
Vermunt et al. (2008)	Behavioural, emotional, and post-traumatic stress problems in children and adolescents, long-term after septic shock caused by Neisseria meningitidis.	• Not a qualitative empirical study
Vermunt, Buysse, Joosten et al. (2011)	Survivors of septic shock caused by Neisseria meningitidis in childhood: Psychosocial outcomes in young adulthood.	• Not a qualitative empirical study

Table 2: Summary of the seven excluded studies from reviewing full text reports

From the three remaining eligible studies (Noyes, 2006; Wallace, Harcourt and Rumsey, 2007; Atkins et al., 2012) a lateral search of the references was conducted to identify any additional relevant studies. No additional studies were identified. The three studies were then subjected to secondary review by two

independent reviewers, SR and PH. Both reviewers independently agreed that all three studies were eligible for inclusion in the review.

Characteristics and quality of included studies

All studies were conducted in the UK involving a total of 51 children and young people that had survived critical illness. All studies used purposive sampling including participants that had survived critical illness due to a range of conditions. Participants' critical illness was primarily due to head/spinal injury (n=18) (Noyes, 2006), sepsis (n=13) (Wallace et al., 2007; Atkins et al., 2012) or malignancies (n= 3) (Atkins et al., 2012). Collectively, the study participants' ages ranged from one-25 years[13], although data were only collected directly from children aged five years and above. Semi-structured interviews were the main form of data collection in all studies - however, one study (Noyes, 2006) included researcher observations and participant drawings as complementary data sources. In addition to collecting data from child and adolescent survivors, two studies (Noyes, 2006; Atkins et al., 2012) included parental accounts.

The quality of studies was assessed using the criteria and grading system devised and adopted by Walsh and Downe (2006) and Downe, Simpson and Trafford (2007). As outlined in Table 3, all studies scored a 'C', indicating that there were some flaws likely to affect credibility, transferability, dependability and confirmability. All studies grounded their research in a range of directly cited literature, they reported their methodology and methods, identified the sampling and inclusion criteria, conveyed a framework for analysis, and demonstrated sensitivity to ethical considerations. However, only Noyes (2006) discussed the epistemological and ontological grounding for the strategy of inquiry, which contributed to the dependability of the study. In addition, Atkins et al. (2012) was the only study to utilise participants to verify findings, thus increasing the study's credibility. However, none of the studies reported: a strategy to locate the background literature; the techniques to ensure transparency of the analysis; or a reflexive account of the research process. Collectively, this contributed to limiting the credibility, dependability, and confirmability of all studies.

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[13] Critical illness was experienced in childhood (≤18 years)

Criteria	Atkins et al. (2012), UK	Noyes (2006), UK	Wallace et al. (2007), UK
Scope and purpose	'To investigate how families came to understand their recovery following their child's admission to PICU' A range of directly relevant literature and theoretical literature cited. However, the location or strategy not reported.	Experiences and meanings of ventilator-dependent childrens health and quality of life Directly related literature cited. However, the location or strategy not reported.	Experience and impact that altered appearance has for survivors of meningococcal sepsis. Directly related literature cited. However, the location or strategy not reported.
Design, methods	Grounded theory No discussion of epistemological/ontological grounding Rational/appropriateness not explored for specific qualitative method Audio tape recorded semi-structured interviews (only with parents in n=4/9 cases)	Heideggerian phenomenology Two phase study: phase 1 exploratory qualitative study; phase 2 case studies. Audio taped interviews (only with parents in n=18/53 cases), researcher observations and drawings (by child/adolescent)	Phenomenology No discussion of epistemological/ontological grounding Audio taped interviews
Sampling strategy Participants	Purposive sampling used however no justification given. Children and adolescent survivors (n=5) from a single PICU and their carers (n=12). Inclusion criteria: child aged 5-16 years at admission; admitted to PICU within the past 8-18 months; child has at least one biological parent participating in the study.	Purposive sampling used and justified. Children and adolescent on ventilators (n=35) with 18 as a result of spinal/head injury. Inclusion criteria: aged 1-18 years; required assisted ventilation for up to 24 hours per day; their parents.	Purposive sampling used however no justification given. Adolescents and young people. (n=11). Recruited from a national database. Inclusion criteria: aged 10-25 years; experienced meningococcal sepsis up to 5 years previously.

Analytic strategy	Emergent, iterative, using constant comparative analysis based on Payne's (2007) grounded theory.	Thematic analysis using Heidegger's hermeneutic circle.	Interpretative Phenomenological Analysis (IPA) used.
		Data was analysed using Atlas Ti™.	Data were analysed and managed by hand.
	Unclear how the data was managed and how the context of the data was maintained during the analysis.	Not clear if data saturation was reached. No evidence that participants verified findings/interpretations.	No evidence of more than one researcher being involved in analysis.
	No evidence of more than one researcher being involved in analysis. However, participant verification of findings noted.	Minimal researcher reflexivity reported.	Not clear if data saturation was reached. No evidence that participants verified findings/interpretations.
	Not clear if data saturation was reached.	Evident that research was sensitive to ethical concerns.	Demonstrates sensitivity to ethical concerns.
	Context described and taken account of in interpretation.		
	However, the use of field notes/interview quotes in discussion of findings were limited.		
	Minimal researcher reflexivity reported.		
	Evident that research was sensitive to ethical concerns.		
Quality rating	C	C	C

Table 3: Characteristics and quality rating of included studies

Criteria	Atkins et al. (2012)	Noyes (2006)	Wallace et al. (2007)
Appropriate data collection methods used for helping children to express their views	✓	✓	✓
Appropriate methods used for ensuring the data analysis was grounded in the views of children / adolescents	✓	✓	✓
Children /adolescents involved in the design and conduct of the study	✓	✗	✗

Table 4: Appropriateness of study methods for ensuring that findings were rooted in the perspectives of children and adolescents

It was evident in all three studies that their findings were rooted in the perspectives of children and adolescents (shown in Table 4). Data collection methods were appropriate for helping children and young people to express their views. Similarly, methods utilised for ensuring that data analysis was grounded in the views of participants were evident in all studies. However, only one study (Atkins et al., 2012) demonstrated that children and adolescents were involved in the design and conduct of the study.

2.3.3   Findings: Data extraction, coding and descriptive themes

All available quotations (n=20) were extracted (Noyes, 2006, [n=6]; Wallace et al., 2007, [n=7]; Atkins et al., 2012, [n= 7]). Respondent quotations that were part of an interview triad (i.e. interview between child, parent and researcher) were extracted in their entirety to maintain contextual understanding of the quote. However, the data of others, such as solely the parent, were not coded or included in the synthesis. Initial line-by-line coding, conducted by JM and SR, identified 81 codes. These extracts and codes were verified by PH who proposed an additional seven codes. JM and SR considered these additional codes and concluded that only five of the suggested seven codes should be included to make a total of 86 codes, which were then verified by PH.

Five major descriptive themes and nine sub-themes (Figure 6) were developed from the codes and refined through interrogation and discussion during PhD supervision.

Descriptive themes	Sub-themes

Long-term psychological and social experiences, impact and needs

Confusion and uncertainty
- Inhibited openess
- Permission to tell narrative

Other people's narratives
- Parental influence
- Meaning making

Focus on former self and normality
- Seeing self as 'normal'

Abandonment
- Mediating between dependence and independence

Transitions and transformations
- Improved vision of self
- Acceptance
- Rationalising new self

Figure 6: Descriptive major- and sub-themes

Confusion and uncertainty

Up to one year after their critical illness, participants, particularly adolescents, indicated complexity and confusion surrounding their life events. When requested by the researchers to report their critical illness experience, participants replied with uncertainty. Responses ranged from forgotten or unknown experiences, such as 'I don't remember much…' or 'it was like a chapter of my life had been taken out', to demonstrating difficulty in constructing and articulating what had

happened to them, such as 'I would like to but it's hard to explain it and stuff….' (Atkins et al., 2012, p. 137). These responses could have been influenced by a multitude of factors such as: embarrassment, researcher-participant parity, and whether there were other people present during the interview. However, uncertainty and reluctance in sharing their story also manifested with familiar people, such as friends and family members.

> *'I've never really told the whole story to anyone before, no I've never*
> *been secretive about it, if anyone wanted to know about it I've told*
> *them. . .'*   *(Atkins et al., 2012. p. 5).*

This inhibited openness appeared to emanate from feelings of anxiety or embarrassment relating to a lack of understanding surrounding their critical illness event. Interestingly, inhibitions also transpired from those who demonstrated some understanding of their critical illness experience. This could have been due to their accounts conflicting with the experiences and reports of others, such as parents.

Collectively, confusion and uncertainty provoked a level of awkwardness in participants and subsequently manifested in permission or approval being required from other people prior to disclosing their own experiences, views and stories.

Other peoples narratives

From this confusion and uncertainty, a picture emerged of how participants came to understand and make sense of their experiences and life events. When asked, participants described how they attempted to understand or gauge a level of clarity through the narratives of others, particularly parents and relatives. This was represented by one participant, who stated,

> *' I don't remember much, it's from my sister, my mum, my mum's*
> *boyfriend, my dad, it all blends in and makes more sense now…..over*
> *the year I've found out more and more and it makes, it puts the picture*
> *together'*   *(Atkins et al., 2012, p.5).*

Other peoples narratives were also used to make sense of their situation allowing them to locate their new self and social identity following critical illness. Parental

narratives appeared to be most significant in forming and influencing views of the critical illness experience, represented in the statement below,

> *'I used to smoke a bit of weed and stuff like that, without my parents knowing and school, I used to bunk my lessons . . . I think it happened for a reason. I don't think my life was supposed to be the way that I was living it and someone was obviously saying, 'hang on hang on, she's wasting her talents'. And therefore I got ill and I've come out of it as a better person.'* (Wallace et al., 2007. p. 127)

Focus on former self and 'normality'

Participants placed an overwhelming emphasis on their former self, a position which they viewed as "normal". They perceived that some families and friends found the person they were prior to the critical illness experience more acceptable than the person they had become. This led them to desire a return to their former self, which for many was unrealistic. The focus on 'normality' provided participants with a drive to assume roles and routines they had undertaken prior to being critically ill. In many cases parents were instrumental in directing the participants' aspirations to retain their former self. One participant demonstrates this by stating:

> *'I know she's [mother] hoping that I would be, that I would get better. I think she should be happy that I'm getting better and like I'm getting back to my usual self yeah'.* (Atkins et al., 2012. p. 4)

However, the emphasis on their former self and 'normality' appears detrimental to participants' overall well-being, particularly where the focus and drive for 'normality' exceed their capabilities. This resulted in participants being unable to achieve what would previously have been normal for them and thus caused a realisation of failure and negative emotions. This is clearly reported by one participant:

> *'When I got home it was a real shock because everyone was just so looking forward to me coming home, and we didn't think about what it would be like when I actually got home, and they'd planned for me to go back to my old school and start the term again and just get back to normal…I just got home and it was just a massive shock (because)*

everything was different…but I tried to go back to school, I went back

for about two days and I just couldn't do it, I was just so upset

because everything had changed.'   *(Noyes, 2006. p. 399)*

Social isolation and loss of identity

Participants described feelings of isolation and abandonment following their critical illness. These feelings emerged from fluctuating social identities that reflected changes to the participants' identity, dependence and ability. Following their critical illness, participants indicated that they were perceived as a novelty in relation to their peers and social group. Interest in participants was initially present after the critical illness but later subsided, thus leaving participants feeling lonely and rejected.

They also indicated how they had to navigate between independence and dependence. Participants reported a dependency particularly on parents for physical assistance, such as activities of daily living, and the maintenance of health, such as being taken to hospital appointments. However, conflicts between independence and this newly realised dependency were reported. This was particularly apparent in adolescent accounts and could be attributed to dependence on others inhibiting their 'normal' personal and social developmental growth trajectory. In response, participants described conflicts when negotiating independence which resulted in emotions such as frustration, for example:

'It was really frustration. I was better, I'd finished chemo, I didn't

have cancer anymore and yet I was still having to be driven

everywhere. . .'   *(Atkins et al., 2012. p. 4)*

Transition and transformation

The final theme encompassed the transitions of self and social identity of participants since their critical illness experience. It is evident that participant transformations did not assume a linear trajectory because recurrent periods of change and adjustment that varied in form and duration were reported. For example:

'I'd been listening to rock music but that changed and then my friends

changed, my friends thought I was totally changing, yeah I didn't feel

myself anymore, everything was changing for me. It was like a chapter

of my life had been taken out….'   *(Atkins et al., 2012. p. 5).*

For some participants, transformations emanated from a confused and complicated or forgotten state, as mentioned in theme 1, where participants' self-identity was unclear due to changes in physical health and social status which created a state of disequilibrium for them. Participants searched for meaning and understanding of their current state by collecting information from others. A period of adjustment then followed enveloped by the aforementioned themes but also provided time for the participant to reflect and rebuild their self and social identity.

As part of the rebuilding and adjustment process, participants reported a level of acceptance in relation to their new identity:

> *'I first of all thought they were going to fade and that, but they*
> *haven't, well they've faded a little bit but they . . . I've sort of accepted*
> *them as permanent now. .'*
>   *(Wallace et al., 2007. p. 128)*

However, in conjunction with this acceptance, the focus of participants' narratives and experiences altered. Participant dialogue changed from constant comparison with their 'normal' and former self to an appreciation and acceptance of their new identity and self. This is illustrated by a participant who states:

> *'I'm so used to them being here that they're actually a part of me now.*
> *I'm really used to them being there, I'm not used to seeing my arms*
> *and legs without them . . . but they kind of define me in a way, in my*
> *own head they kind of define me. I don't know what the definition is*
> *either, they're just essential for me to exist within myself..'*
>   *(Wallace et al., 2007, p. 128)*

Participants also described changes in how they perceived themselves and how those views had been adjusted since their critical illness. This participant reports:

> *'. . . before I was like, 'oh I'm really fat' and I wasn't fat. I look at*
> *photos now, 3 years ago and I'm like 'oh my God I was really skinny.*
> *But at the same time you know, I know for a fact that that period I was*

> *complaining to my friends that I was fat and stuff . . . and now it's like*
> *'oh, whatever'.* (Wallace et al., 2007, p. 129)

It was evident that, during this transformation period, participants reflected on their current status, rationalising their experiences and subsequent outcomes either in line with what had happened to other people who had experienced similar events such as:

> *'I know a girl who lost both her legs. She was on the news. That was*
> *actually upsetting to see as well, 'cause I was like, I've got all my*
> *body left and she hadn't, but . . . I think I was quite lucky from that,*
> *just seeing that.'* (Wallace et al., 2007, p. 129).

Or by focusing on what could have happened:

> *'I actually at some point felt that I knew I was going to die . . . so your*
> *life does flash before you....when I first woke up to this then I*
> *contacted all my old friends . . . and just said hello, let's meet up and*
> *have coffee, and re-evaluated my entire life...'*
> (Wallace et al., 2007, p. 128)

It is evident from this that participants demonstrated a level of resilience during their transformation. Participants began to rebuild and mediate a new or adapted self and social identity, which encapsulated their journey and current physical, psychological and social status.

2.3.4 Analytical synthesis and themes

The five major themes identified from the descriptive synthesis were subjected to interrogation with an aim of producing higher order themes and defining the relationships between them (Cruzes and Dyba, 2011). Four analytical themes, 'missing picture'; 'rebuilding picture'; 'new-self and social identity'; with the cross cutting theme of 'transformation' were formulated. The synthesis of these new analytical themes culminated in the creation of a conceptual framework (Figure 7) that represented the inter-relationships between each theme and the central phenomena in question.
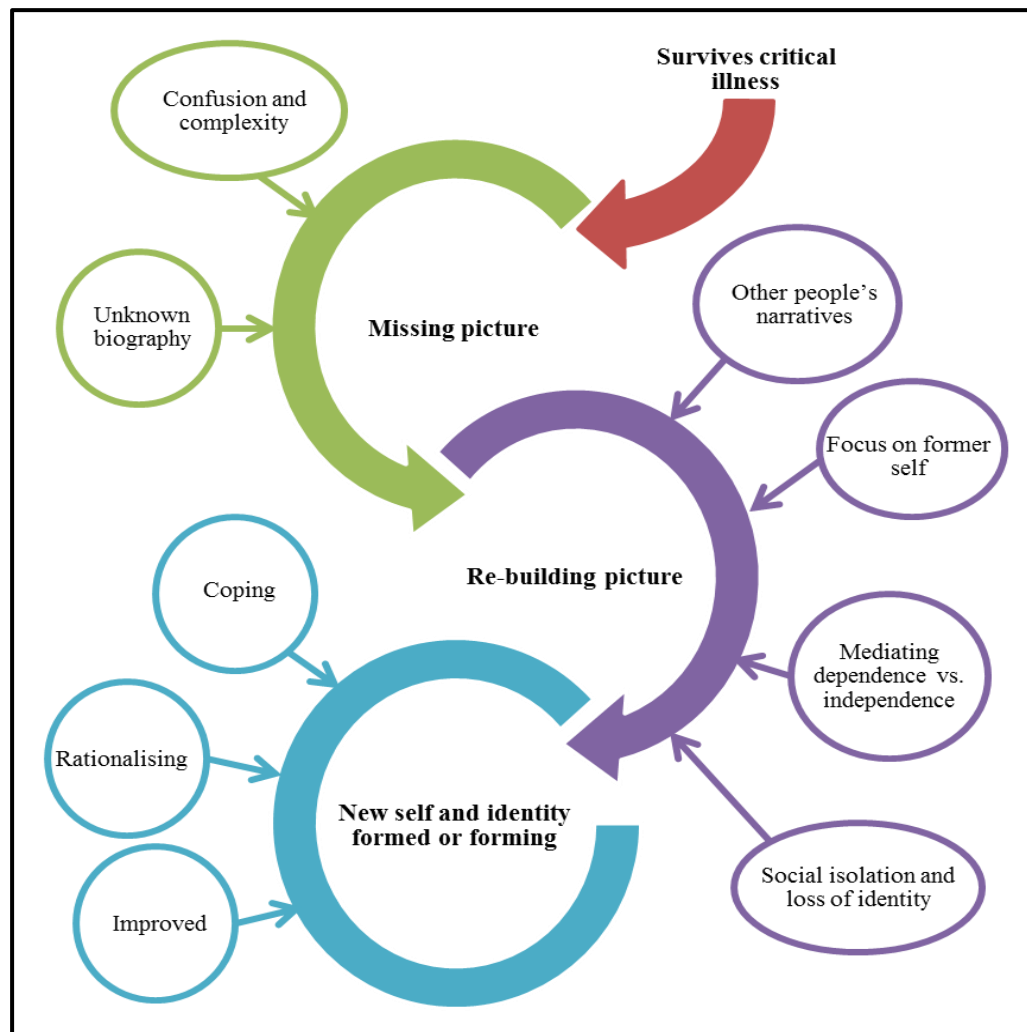
Figure 7: Conceptual schema of analytical themes

Missing picture

It is apparent from survivor self-reports that the initial adversity encountered emanated from confusion and ambiguity in relation to their biographical narrative. Lack of clarity surrounding their critical illness experience rendered children and adolescents perplexed and unable to comprehend or share their story. This denied survivors the meanings and explanations required to locate their self and social identities within the world. This period following critical illness was identified as the theme 'missing picture' and negatively impacted on the psychological and social status of survivors.

Rebuilding picture

From this period of ambiguity ('missing picture'), it was evident that a pursuit to regain control and understanding over the survivor's new self subsequently ensued

('rebuilding picture'). This dynamic phase encompassed a number of processes and influences. Through the collection of other people's narratives (particularly parents), survivors began to piece together and rebuild the missing picture. However, this process was not without ongoing adversity. Survivors had to navigate conflicts between their own and other people's utopian desires for them to resume their former 'normal' self. For many survivors this involved mediating between their expected or perceived abilities and the realities of their new, and potentially altered, being. Rebuilding their self and social identities required realisation, adjustment and realignment of survivors' expectations and norms. For some survivors this exposed them to additional adversity. Abandonment, psychological and social isolation were experienced either as a result of the dynamics of the social group not aligning to the survivor or vice versa. Collectively, exposure to this adversity contributed to the realisation that the self and social identities were transforming and being redefined.

New self and social identity formed or forming

This phase or period of transformation continued until survivors came to the realisation and acceptance of the newly-defined self. For some survivors this was not a finite stage but continued as a dynamic process. This phase also recognised a change from mediating between unachievable expectations, to rationalising and implementing coping mechanisms to deal with the reality of themselves as a transformed or transforming physical, emotional and social being.

2.3.5   Systematic review discussion

Psychological and social adversity

The findings from this review appear to provide novel insights into how long-term psychosocial impact and experiences are exclusively perceived and reported by child and adolescent survivors.

Psychological and social adversities transpire from biographical disturbances and conflicting identities. It is evident that these findings contrast with existing literature (presented in section 2.2.3) which claims that psychological impact following critical illness predominates from the iatrogenic nature of the PICU, such as invasive interventions, noisy environment, infusions of medicines with

side effects (Rennick and Rashotte, 2009). This review identified that psychological and social impact can emanate from a 'missing picture'. Although the utilisation of this term is novel, similar themes have been reported in the adult ICU and wider healthcare literature. Failure to recall a critical illness experience is common in adult ICU patients (Stein-Parbury and McKinley, 2000), emanating from delirium and hallucinations which have been attributed to polypharmacy and physiological changes (Truman and Ely, 2003; Skrobik, Bergeron, Dumont et al., 2004). A recent review and synthesis of qualitative literature from adult ICU survivor self-reports categorises this theme under 'transformations of perception: unreal experiences and dreams' (Cutler, Hayter and Ryan, 2013, p.149). Similar to the findings from this review, Cutler et al. (2013) purport survivors experienced an altered sense of reality and perception that led to negative emotions and distress. However, this was reported to occur during or immediately after critical illness, with conflicting findings presented as to whether survivors engaged with their critical illness event in the longer term (Cutler et al., 2013). This indicates that, despite this phenomenon being evident in both adult and childhood critical illness survivor self-reports, the way in which it manifests appears to differ. Although it cannot be refuted that the aforementioned adversity could be influenced by exposure to PICU, the findings of this review suggest that during long-term survival, adversities unfold and manifest that are separate to the direct intensive care experience.

Through engaging with health psychology and medical sociology literature, parallels can be drawn between findings relating to survivors' 'missing picture' identified in this review and concepts and theories proposed in the literature. Cowie (1976) and Maclean and Cockshutt (1979) describe how patients who experience heart attacks enter a 'critical situation of uncertainty'. This uncertainty emanates from the patients having little or no idea as to what has happened, thus confusing or disrupting an individual's biography, although it is evident that differences exist between the patient group where this phenomenon was reported and that of the patients in this study (e.g. adults vs. children, conscious state during illness vs. unconscious state). Therefore, it could be suggested that confusion and uncertainty experienced following a life-threatening event are not unique to child and adolescent survivors of critical illness.

Rebuilding and transformations

From initial uncertainty a dynamic process of rebuilding and transformation occurs. The initial stages of this process involves the collection and acquisition of stories surrounding the critical illness experience to provide survivors with a platform to reflect upon their core values and prioritize things that were important to them. The use of others people's narratives could be explained by Taylor's (1983) 'Theory of Cognitive Adaption' which defines the period post illness as 'a search for meaning'. Although this theory was constructed from research with adult female breast cancer survivors, Taylor (1983) identifies that meaning making following a life-threatening event is essential to understand the cause and significance of the event. Specifically to critical care, Cutler et al. (2013) identifies that adult survivors also use other people for clarification and meaning making following critical illness. However, in contrast to this review's findings, health professionals were a significant group of informants for adult survivors and were used for narrative verification, safety and security (Cutler et al., 2013). It is important to note, however, that both Taylor's (1983) theory and the Cutler et al. (2013) review were based on empirical research with adults and so the influence of the cognitive developmental level of participants was not considered. Furthermore, although Ogilvie, McCloughen, Curtis et al. (2012) did include two studies with adolescent survivor reports, the potential influence of the dynamic stage of life, such as physical, psychosocial and cognitive development, on their accounts and experiences was not evaluated.

Despite the utilisation of other people's narratives to provide some elements of meaning and to rebuild their picture, survivors continued to endure psychological and social impact. Survivors focused on their former 'normal' self and resisted their new self and social identity. Bury (1982) describes a similar phenomenon as an upset in relation to 'internal and external realities' where the survivor encounters a 'biographical shift' from that of a perceived normal trajectory to one that is abnormal and possibly 'inwardly damaging'. This could explain why PICU survivors place an emphasis on their former being and are resistant to something that is as described as 'damaging and abnormal' (Bury, 1982). However, what is not explored by Bury is the impact of resistance as findings suggest that on-going resistance to the new self and social identity is also damaging. It could be argued

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that, without adjustment, the survivor will endure further negative psychological and social adversity.

Charmaz (1983) also provides an interesting insight into the rebuilding of self following illness, specifically chronic illness. She proposes that experiencing illness is a social and psychological process where the inner dialogue between I and me changes as well as survivors' own definitions of experiences. Charmaz (1983) identifies that survivors have a restricted life imposed upon them where values of independence and individualism are challenged. Moreover, survivors are unable to exercise choice in valued activities resulting in self-image not being maintained. However, similar to the rebuilding process identified from the analytical themes, Charmaz (1983) reports that this adversity is the foundation from which re-evaluation and change occur.

Psychological and social needs

Clearly, childhood survivors of critical illness have a number of outstanding needs that manifest in the long term. These include: a need for information, to alleviate any uncertainty or ambiguity surrounding their life in order to reassemble the missing or partially formed picture; a need for time, to grieve for their former self, to explore and understand their experiences (meaning making), and to reflect and rebuild their new self and social identities; and a need to accept, to allow for adaption/adjustment to their new physical, psychological and social reality. However, it is apparent that these needs identified are only perceived needs as identified by the researchers conducting this review and not the children and adolescent survivors themselves. This review has identified a distinct scarcity of research exploring psychological and social needs as experienced by the child and adolescent survivors of critical illness.

Strengths and limitations of the review

Although many hundreds of papers were identified that explored or quantified the impact of illness in childhood, very few fulfilled the inclusion criteria for this review. The search strategy had high sensitivity and yet, despite measures, such as search filters to maximise specificity, specificity remained low. This occurrence of a trade-off between sensitivity and specificity is reported within the literature, with highly sensitive strategies having low levels of precision and vice versa

(Petticrew and Roberts, 2010). However, for reviews where the 'intervention', or as in this study the 'phenomena of interest', is difficult to define, it is recommended that sensitivity should be maximised at the risk of specificity to ensure an exhaustive search (Petticrew and Roberts, 2010).

As part of a qualitative systematic review, the trustworthiness of the synthesis should be assessed (Cruzes and Dyba, 2011). Similar to the quality criteria used to assess each paper, suggested criteria for examining the trustworthiness of a review are: credibility; confirmability; dependability; and transferability (Lincoln and Guba, 1985).

Credibility relates to the how well the data and analytical methods address the proposed focus of the review (Cruzes and Dyba, 2011). The focus of this review is clearly outlined with firm rationale provided in relation to the selection of contexts, participants and approach to the collection of primary studies. The data segments extracted allowed for meanings to be retained without becoming difficult to manage. In addition, representative segments of the data have been reported with the findings to exemplify judgements made in the coding and thematic synthesis of the data.

Confirmability of the synthesis relates to how the data was coded and sorted and whether agreement could be obtained from other researchers (Cruzes and Dyba, 2011). As advocated by Graneheim and Lundman (2004), multiple independent reviewers were involved in identifying and confirming codes and themes. Through a consensus approach, only those articles that were agreed by all reviewers were included in the synthesis.

The dependability of the synthesis relates to how much the data and interpretations changed during the review process (Cruzes and Dyba, 2011). The extraction, coding and synthesis process is clearly identified in this review with decisions during the synthesis process being reported. To enhance the dependability of the findings, reviewers were reflexive during the analytical process which involved critically examining the themes generated against their pre-suppositions.

Cruzes and Dyba (2011) stipulate that the extent to which the findings from a review can be transferred to another context or group can ultimately only be

decided by the reader. However, attempts have been made to facilitate this by providing a comprehensive description of the context and characteristics of the studies included with an in-depth presentation of the findings.

A potential limitation of this review is the exclusion of relevant research studies that were published in non-English languages as no non-Western databases were searched. This could have provided an ethnocentric perspective of the topic under investigation and limited the transferability of the findings to other contexts and their health care systems. This highlights the scope for a review of international (non-English speaking) research in this field. Conversely, contextual homogeneity is advocated by some authors in relation to the ability to conduct a thematic synthesis of findings. By having all participants from the same geographical region (country) and who have experienced the same healthcare system, it could be argued that this strengthens the synthesis and facilitates transferability of the findings.

Within the literature, advice varies according to the number of studies required to yield a meaningful synthesis. Noblit and Hare (1988) and Campbell et al. (2003) advocate between four and six studies, whilst other authors have recommended significantly more (Paterson, Thorne, Canam et al., 2001; McDermott, Graham and Hamilton, 2004; Sandelowski and Barroso, 2007). It is, therefore, evident that, as only three studies were included in this review, the meaningfulness of the thematic synthesis and subsequent findings could be brought into question. Even so, a rigorous and systematic search for potential studies was conducted with a clear and transparent process for study selection being used, thereby increasing the relevance.

In addition, it could be argued that the exclusion of quantitative studies could have limited the scope of this review as there were a larger number of these studies than qualitative. However, the integration of quantitative studies would have undermined the purpose of the study, which was to gain an in-depth and rich account into the phenomena as reported by children, adolescents and young people.

2.4   Conclusion and gaps in the literature

2.4.1   Gaps in the literature

The systematic review and thematic synthesis of qualitative studies have provided novel insights into long-term psychosocial experiences of surviving childhood critical illness. Findings indicate that long-term survival can involve a complex array of adversity, which emanates from biographical disturbances and the misalignment between an idealistic focus on 'normal' prior self and the reality of the survivor's changed being. Subsequently, transformation occurs in an attempt to overcome the adversity faced. For some, this involves acquiring and exploring other people's stories in an attempt to fill their missing picture. In addition, survivors navigate new conflicts that present such as dependence versus independence where new social identities are imposed upon them.

This review has identified a paucity of published research covering children's accounts of their long-term experiences following survival of critical illness. Although multiple factors that may be influential have been illuminated, the exact trajectories, as well as intrinsic and extrinsic influences, are unclear. This is confirmed by the proposed conceptual framework (Figure 7, page 45) that lacks details relating to the mechanisms and processes involved in long-term survival. Subsequently, it is uncertain if outcomes are isolated to specific times, if they are present throughout the experience of survival, or if and how they may change over time (Manning et al., 2014). This confirms previously reported deficits in this field of literature (Rennick and Rashotte, 2009) and identifies that further inquiry is needed that comprehends the context and potential multi-faceted nature of the phenomena.

Collectively, existing evidence harbours deficits that inhibit a comprehensive understanding of the long-term psychological and social experience of survivors following childhood critical illness and PIC. This aligns to the assertion by Dow, Kenardy, Long et al. (2012) that understanding children's outcomes and experiences following survival of PIC significantly lags behind advances in medicine. Furthermore, previous studies have predominantly focused on uni-dimensional aspects of children's survival from critical illness, by compartmentalising or deducing experience into either physical, functional,

psychological or, in rare cases, social domains. Exploring both psychological and social experience of PIC survival could provide a more comprehensive understanding of this phenomenon. Therefore, further research in this field should utilise suitable and effective methods to capture children's and adolescents' experiences, views and perspectives, which is underpinned by a collaborative ethos.

2.4.2   Scope of this empirical inquiry

It can be concluded from the literature reviewed in this chapter that understanding of the long-term psychosocial well-being of PIC survivors within the context of their lives is absent. Therefore, further exploratory research is required to:

• Provide an in-depth and contextual understanding of how psychosocial well-being is described and experienced by child and adolescent PIC survivors in the longer term ($\geq$ six months post-PICU discharge)

• Focus on child and adolescent survivors' accounts within the contexts of their lives

• Explore survivors who have been previously excluded from research in this field, such as those children with cognitive or developmental impairment.

• Explore the phenomenon holistically (individual and social worlds) and over time in order to map and understand any trajectory that might manifest.

Collectively these formed the basis for the aims and objectives of the study presented in this thesis and were addressed using the research approaches outlined in the next chapter.

Chapter Three
Methodology and methods[14]

3.1   Introduction

This chapter presents the methodological and procedural approaches employed in this study in order to explore PIC survivors' long-term psychosocial well-being within the context of their lives.

The chapter begins by outlining the aims and objectives for this empirical inquiry that address some of the deficits in the existing literature (outlined in Chapter two, page 52). As children and adolescents were central to this study, the ethical, methodological and practical challenges of conducting research with this group are expounded. A discussion of how these considerations informed the strategy, including the philosophical orientation, study design, and approaches used is presented. The research setting and sampling framework will then be described and the procedures for recruitment and consent outlined. Methods to gather, organise, analyse and ensure the quality of the data collected will be presented.

3.2   Study aims and objectives

The main aims of this study were:

1. To develop an in-depth understanding of how PIC survivors construct long-term psychosocial well-being within the context of their lives by:

   (i) Collecting and exploring the stories of PIC survivors and the accounts of significant people in their lives;

   (ii) Focusing on the psychological and social worlds within these stories to illuminate understanding of how children, adolescents and significant others construct, experience and make sense of their psychosocial well-being.

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14   A substantial part of this chapter has been published: Manning, J. C., Hemingway, P., & Redsell, S. A. (2014). Protocol for a longitudinal qualitative study: survivors of childhood critical illness exploring long-term psychosocial well-being and needs—The SCETCH Project. **BMJ Open** 4(1).

2. To develop an understanding of the long-term psychosocial well-being of childhood PIC survivors within and across contexts by:

(i) Comparing and contrasting PIC survivor and significant other accounts and assessing them for patterns.

(ii) Synthesising contextualized instances within and between case studies.

3.3   Methodology

3.3.1   Ethics, child-centeredness, and collaboration

Despite a plethora of guidance[15] on conducting ethical health research, there appear residual anxieties and resistance to inquiry on risky or sensitive topics (Dickson-Swift, James, Kippen et al., 2007), or with 'vulnerable' populations such as children (Flewitt, 2005; Nind, Wiles, Bengry-Howell et al., 2013).

This study aimed to explore potentially sensitive topics with children and adolescents who have been defined historically, socially and within the literature as a 'vulnerable' group. Conducting research with children and adolescents poses a number of ethical, methodological and practical challenges (Morrow and Richards, 1996; Christensen and Prout, 2002; Flewitt, 2005; Kirk, 2007; Graham, Powell, Taylor et al., 2013; Carter, Bray, Dickinson et al., 2014) which predominantly relate to power and consent (Morrow and Richards, 1996; Kirk, 2007). Stark reminders in history identify that harm can and has occurred to children through involving them in research[16] (Carter et al., 2014). Until recently this has been attributed to research being developed and conducted by adults, for adults, within an adult world. Despite these challenges it has been recommended that this should not deter children's involvement in research as the process and products of ethical, child-focused inquiry can have many benefits (Royal College of Paediatrics and Child Health Ethics Advisory Committee, 2000; Newman and Kaloupek, 2004; NSPCC, 2013). If research is to be undertaken in the 'best interests of children and adolescents themselves' (Lewis, 2004, p. 1) then

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[15] From governmental, professional and non-profit organisations (such as charities).

[16] Examples include the Willowbrook Study in New York (USA) where children were deliberately infected with hepatitis strains without informed consent.

researchers must acknowledge and address ethical, methodological, and legal issues that might arise. Two strategies, (1) child-centred and (2) collaborative approaches, were used to underpin this study in order to address ethical and methodological issues of conducting research with children (Thomas and O'Kane, 1998).

A child-centred approach to conducting research has evolved from disciplines such as social anthropology, education, sociology, psychology, geography and social work (Freeman and Mathison, 2009). This stance upholds the view that children are knowledgeable, interactive, social beings that influence and are influenced by their social world (Christensen and Prout, 2002; Freeman and Mathison, 2009; Carter and Ford, 2013). Boyden and Ennew (1997) suggest a child-focused approach acknowledges challenges that may be faced when attempting to elicit their often marginalised views and perspectives within a highly hierarchical adult society. However, this stance has been criticised as there is no automatic position that researchers and their underpinning methodologies should adopt in order to accommodate children's varied cognitive abilities and differing ethical standards (Robinson and Kellett, 2004). As intimated in the UN Convention on the Human Rights of the Child (United Nations, 1989), children's and adolescents' attitudes and experiences can only be obtained by engaging directly with them and by treating them as independent actors (Mahon, Glendinning, Clarke et al., 1996; Christensen, 2004; Dockett and Perry, 2007). It has, therefore, been proposed that when researching young lives it is essential that a collaborative, child-focused approach is utilised as active participation respects children's rights (Crivello, Camfield and Woodhead, 2009).

This study aimed to ensure that children and adolescents were central, and involved in order to communicate their own views, experiences and needs (Carter and Ford, 2013). In addition to recognising children and adolescents as autonomous social actors, this study also viewed children and adolescents as active participants in the research. This collaborative position transcended the design and methods utilised, as children were empowered to make decisions and choices about involvement, methods and conduct of the inquiry. However, this was not in its entirety pre-defined but evolved during the inquiry (Holland, Renold, Ross et al., 2010).

In addition to participants' active involvement in the study, other children, adolescents and their families helped develop the research design. This upheld the collaborative ethos of this study and aimed to ensure the relevance and quality of the research (Savory, 2010; INVOLVE, 2012, 2013). Seven children and adolescents (aged six-15 years) who had varying experiences of healthcare (e.g. chronically unwell, healthy) and three parents (two mothers, one father) volunteered to provide guidance and advice in developing the study. In line with guidance, volunteers received a gift voucher (£5.00) as a token of appreciation for their involvement (INVOLVE, 2010).

Ultimately, this study adopted the stance that, when conducting real world research, the existence of the 'perfect' design is conjectural. Planning and conducting research outside a vacuum (e.g. in the real world) is messy, multi-variant and complex (Robson, 2011). Therefore, the optimal study design for inquiry in the real world requires decisions and trade-offs (King, Keohane and Verba, 1994; Shadish et al., 2002). However, children and adolescents were central to this inquiry and so any decisions to achieve optimal study design were evaluated in terms of maintaining the ethical well-being of the participants. Due to their entwined existence within this inquiry, I will expound the decisions in relation to ethics, child-centredness and collaboration throughout the reporting of this chapter.

3.3.2 Philosophical orientation

Philosophical orientations provide a set of interlocking traditions (Monti and Tingen, 1999; Creswell, 2009) which guide the decisions researchers make in how they conduct inquiry and view the products of it (Guba and Lincoln, 1994). Inquiry in the social sciences is qualitatively different from that of the natural world, because the social world is formed of humans with self-consciousness and social groups (Dilthey, 2003; Benton and Craib, 2011). Therefore, a range of epistemological (knowledge) and ontological (truth) viewpoints from which to position these assumptions exist (Guba and Lincoln, 1994; Avis, 2003).

Researcher reflections, suppositions and aspirations

In the absence of a unifying philosophical orientation it is the responsibility of the researcher to define the position in which the strategy and products of the inquiry

should be viewed (Klein and Myers, 1999). It was evident that the philosophical position of this study was influenced by my own lens and the motivation and purpose of this study.

I came to this research as a health practitioner, with a professional identity as a practising children's intensive care nurse which influenced how I viewed the world around me. As a children's nurse I ascribe to a family-centred, holistic model of nursing practice, which comprehends the whole patient and their family in the assessment, planning, delivery and evaluation of care (Galvin, Boyers, Schwartz et al., 1999). This approach is individualised, underpinned by viewing the child as irreducible into organ systems or activities, but perceives mind and body as intertwined as a multi-faceted human being (Bleicher, 1982; Hutchfield, 1999). However, I view human beings as interactive social agents that are informed by the social world around them. This aligns with the assumption that people 'both construct their worlds and are constructed by their worlds' (Kincheloe, 2004, p. xii), as they engage in daily practices.

The purpose of this empirical inquiry was to explore and understand PIC survivors' experiences. However, unlike the existing literature which provides a short-term, uni-dimensional view, this study aimed to explore the interplay between the survivors' self and social worlds. The principal motivation was to harness the survivor's voice as this appeared muted due to salient empirical research viewing children as either objects or subjects and focusing on adults as proxies. Moreover, due to perceived limitations of certain groups or ages of children, such as those with cognitive impairment or young children, sampling criteria have excluded certain children's views. Christensen and Prout (2002) suggest that how children are viewed by the researcher has fundamental implications for the research approach employed. Therefore, this study viewed children as a diverse group of individuals 'with particular perspectives, experiences and life-worlds' (Carter et al., 2014, p. 35), thus ascribing to the tenet that we can learn about children and their experiences from children.

From these aspirations it was evident that this study aligned broadly to an interpretivist-constructionist philosophical orientation.

Interpretivist-constructionist orientation

Research that seeks to understand human experience and behaviour is broadly situated within an interpretivist worldview (Benton and Craib, 2011). The term 'interpretivist' is used synonymously within the literature with other terms such as constructivist, naturalistic, and hermeneutics (Denzin and Lincoln, 2011, p.12), due to their common 'intellectual heritage' (Schwandt, 1994, p. 119). Inquiry conducted from this standpoint aims to gain insights into 'the complex world of lived experience from the point of view of those who live it' (Schwandt, 1994, p. 118). Therefore, from this philosophical stance, the survivors and other participants in this study were viewed as active agents, involved with, and interpreters of, their life experiences and social world (Forbes, King, Eastlick Kushner et al., 1999). By studying the 'meanings' they construct and negotiate through their language and interactions, insights into their individual and social worlds can be gained (Delanty and Strydom, 2003).

Interpretivists claim there is no objective, value-neutral knowledge as all knowledge is interpreted and constructed (Hammersley, 1992, p. 52; Chen, Shek and Bu, 2011). Unlike the natural world, where a particular action consistently produces a given result, social actors do not homogeneously react to stimuli (Benton and Craib, 2011). Subsequently there are no social laws to uncover, as norms and values do not exist independently from individuals (Delanty and Strydom, 2003). Constructionists focus on discourse or the social activities that transpire between people (McNamee, 2004). Meanings are negotiated and co-constructed through interactions with other agents in their social world and are created and re-created as a result of personal perspectives within context. As a result, knowledge and knower are interdependent and so there are multiple and sometimes conflicting accounts of experiences that are constructed, but all remain valid (Rubin and Rubin, 2005). By ascribing to an interpretivist-constructionist standpoint, it upholds the view that children's and adolescent's accounts may differ from that of others but remain valid. Furthermore, it comprehends the reciprocity between the individuals and their social world in the generation and interpretation of knowledge.

In relation to epistemology, research from an interpretivist-constructionist position focuses on the relationship between the 'knower' (participant) and the 'would-be

knower' (researcher) (Berger and Luckmann, 1966). Some researchers within this paradigm align to a realist view, suggesting that data directly provide information about the social world or phenomena (Chen et al., 2011). However, relativists assert that experience cannot be captured, instead it is through culture and discourse that re-constructions of experiences within different contexts can be explored (Willig, 2008). This relativist standpoint had greater congruence with the contextual variations within this study.

Ontologically, this study viewed the social world as 'in the making' (Elliott, 2005, p.18) with multiple realities (Benton and Craib, 2011). Reality is a product of one's own creation and each individual sees and interprets the world and their experiences through personal belief systems (Crotty, 1998; Denzin and Lincoln, 2005). From this philosophical orientation the role of the researcher is situated within the inquiry to explore experiences and co-construct reality (Chen et al., 2011). However, I am culturally different from the participants, I am not a child, nor a PIC survivor. Therefore, I recognise that I cannot directly translate from another's world - instead I view my role as re-constructing and interpreting it. Hence the researcher is viewed as a vehicle by which participants' experiences are co-constructed, interpreted and revealed (Riessman, 2008). Whilst this standpoint upholds the main suppositions of the study, the subjective, cultural and context-bound nature of the products might limit application to clinical practice. However, shared meanings and discourses have been shown to exist between different cultures and contexts, which have been effectively used to inform policy and practice (Greenhalgh, 2007). For findings to be translated into practice, it is imperative that the contribution of the researcher can be scrutinised by the audience to ensure moral and ethical rigour (Kvale, 1996; Bishop and Shepherd, 2011). In this study this will be achieved by providing a transparent and reflexive account of the situationality of the researcher within the research process.

3.3.3   Study design

Selecting an appropriate qualitative study design

In order to develop an in-depth understanding of unknown and potentially complex phenomenon, a qualitative research design appeared most suitable (Pope and Mays, 1995; Silverman, 2010). Qualitative research is undertaken with

context-bound, rich and detailed data and involves rigorous interpretation, in order to comprehend the phenomena under investigation. However, variations exist in relation to: the strategy of inquiry; the information that is collected; and how this information is interpreted and understood (Blaikie, 2007; Wertz, Charmaz, McMullen et al., 2011). The study purpose and philosophical viewpoint should govern the selection of the research approach adopted (Creswell, 2009). I therefore formulated a list of criteria to inform this choice (Table 5).

A research design that allowed for :
• The in-depth exploration of long term psychosocial well-being from individuals, within and across contexts;
• The longitudinal collection of data;
• Views, perspectives, meanings, and experiences of participants to be captured;
• A focus on contemporary and historical events;
• Appreciation of research participants as individuals as well as social beings;
• The role of the researcher in the research to be recognised;
• The use of child and adolescent focused mediums to collect data;
• The promotion of inclusion and respect of participants that varied in ability;
• Findings applicable to clinical (nursing) practice.

Table 5: A list of criteria used to select an appropriate study design

Traditional research designs from the social sciences are commonly used in applied qualitative health research (Thorne, 2011). There continues to be significant dominance of these approaches in nursing particularly phenomenology, a strategy for understanding participants' lived experiences; grounded theory, a strategy for developing theory; and ethnography, a strategy for describing and understanding a social group or system (Lingard, Albert and Levinson, 2008; Reeves, Kuper and Hodges, 2008; Smith, Bekker and Cheater, 2011). However, as this study aimed to explore how the phenomenon was constructed and experienced longitudinally, from the accounts of individuals as well as within and across contexts, it was evident that no single approach upheld the objectives of this study in their entirety.   Therefore, I searched for an alternative research design.
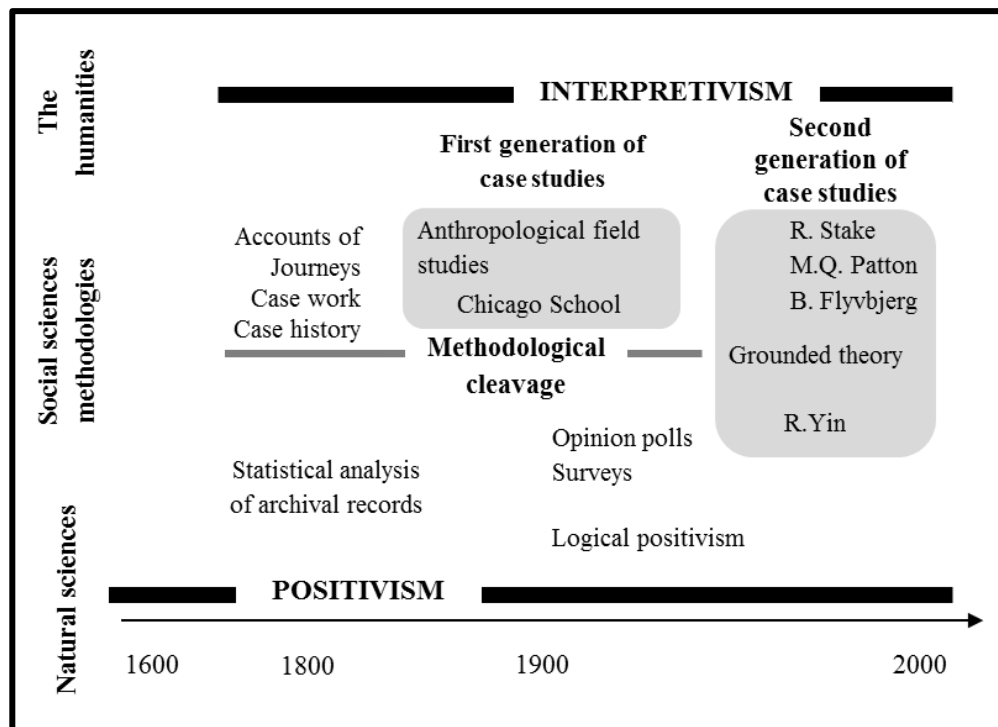
Figure 8: The history of case study methodology[17]

Despite having its early roots in the social sciences (as shown in Figure 8), in recent years case study research has gained increasing popularity within healthcare (Zucker, 2001; Luck, Jackson and Usher, 2006; Rosenberg and Yates, 2007; Anthony and Jack, 2009; Crowe, Cresswell, Robertson et al., 2011). The case study approach is reported to provide a platform for an in-depth, holistic, investigation of a phenomenon situated within the socialised group to which it belongs (Stake, 1995, 2006; Yin, 2009; Swanborn, 2010; Crowe et al., 2011). This is achieved through the collection of data via a number of methods and sources over a period of time (Stake, 1995; Creswell, 2009; Yin, 2009) which offers converging lines of inquiry (Murphy, Dingwall, Greatbatch et al., 1998). Case studies provide a flexible research strategy that allows for the contextualised description, exploration or explanation of contemporary events, processes, relationships, and/or problems (Pegram, 1999; Dockett and Perry, 2007; Anthony and Jack, 2009).

Due to methodological and theoretical plasticity, case study research can vary its focus, from an individual to a collective, and the types of data collected, including qualitative, quantitative or mixed methods (Rosenberg and Yates, 2007). Issues

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[17] Adapted from Johansson (2003, p.7).

relating to generalizability and confusion with similar terminology (such as case reports) have contributed to case study research having a lower status when compared to other approaches (Flyvbjerg, 2006; Crowe et al., 2011).

For this study, the case study approach satisfied the multiple objectives by allowing for the in-depth and contextualised exploration of phenomena of individuals, contextualised units, and across groups. Furthermore, Stake's approach to case study research is underpinned by a broad interpretivist worldview (Stake, 1995) which was congruent with the philosophical tenets of this study and was therefore adopted.

Collective, longitudinal, case study design

Stake (1995, 2006) has categorised case study research into three main types:

- Intrinsic, where the focus is on gaining a deeper understanding of a unique phenomenon which is innately bound by the case,

- Instrumental, where a particular case is studied to gain a broader insight into an issue and to facilitate understanding of something else,

- Collective[18], where a number of instrumental cases are simultaneously or sequentially explored to inquire into a particular phenomenon.

This study aimed to explore context-bound, individual experiences of PIC survivors, as well as understanding how this manifested across instances. A collective case study approach such as this has been suggested to produce more compelling and robust evidence (Stake, 2006). The ultimate aim of the collective case study is to draw assertions as to the unity or deviance of the phenomenon or 'quintain' (Stake, 2006). This is achieved through the merging or aggregating of findings across cases allowing for the degree of congruity to be explored across instances (Stake, 2006). For this study, the quintain was the psychosocial well-being of PIC survivors. The case study approach allows for a phenomenon to be explored longitudinally as well as across different contexts (Ruspini, 1999). The interpretation and understanding of the quintain involves searching for patterns

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[18] Also referred to as 'multiple' within the literature.

with repetition of instances giving indication of 'interactivity' between cases and across contexts (Stake, 1995, 2006).

Defining the case

Defining the case determines the scope of the inquiry (Stake, 1995, 2006; Yin, 2009; McIntosh and Stephens, 2011) and should begin by identifying the tentative case. Once identified, further refinement is made to the case's spatial, such as the people involved, and temporal, such as the duration data will be collected, boundaries (Creswell, 2007).
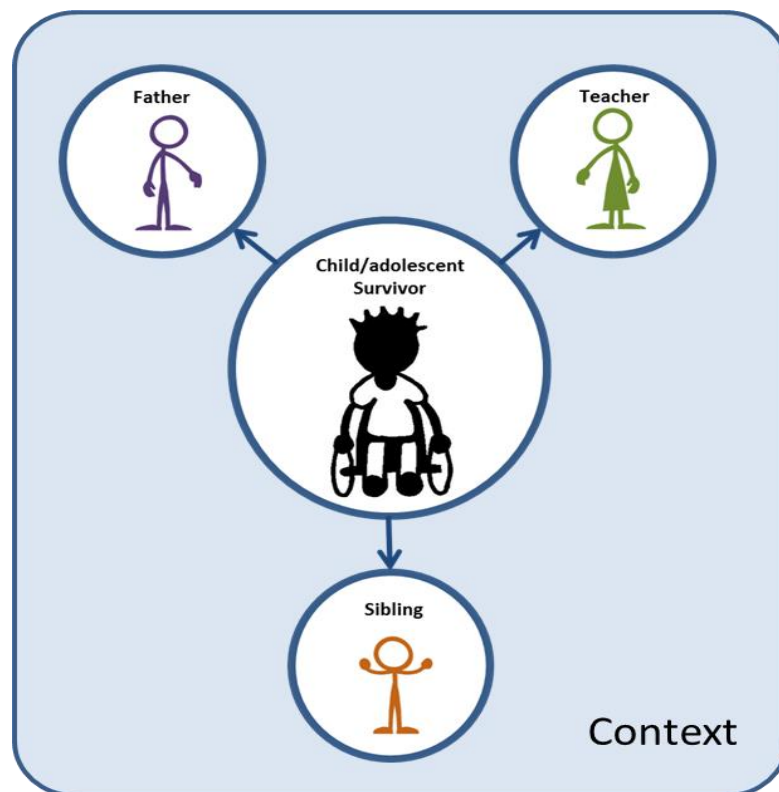
Figure 9: An example of a potential case study composition

The case should be built around the 'main unit of analysis' which is determined by examining the principal research questions, or aims and objectives. Central to this study and its objectives were the PIC survivors of an acute life-threatening critical illness. PIC survivors were defined as the main unit of observation and analysis as they were central to each case (Figure 9).

As outlined in Chapter two, surviving critical illness has implications on significant others in the survivors' lives (Shudy et al., 2006). Although the aims and objectives of this study focused on PIC survivors by including significant

people in their lives, differing perspectives, considerations and values can be collected for comparison (Crivello et al., 2009; Harden, Backett-Milburn, Hill et al., 2010). This provides opportunity for researchers to explore the power and influence that care-givers and other adults have in a child's life (Crivello et al., 2009). There is also the benefit of including the views and experiences of other children, such as siblings or friends (Emerson and Giallo, 2014).

Those deemed significant in the survivor's life were also included in the case study. To uphold the collaborative ethos of the study, the PIC survivor selected the significant others based on whether they were an important person in their life. These could have included main care-givers, parents or guardians, other family members, individuals from education or healthcare, or individuals from wider social groups.

Data gathering and analysis

Case studies aim to reveal the potential complexity and multifaceted nature of a phenomenon by gathering a variety of information from different sources and analysing this using a range of methods (Stake, 1995; Crowe et al., 2011). Stake (1995) asserts that the types of data gathered and analytical methods used are dependent upon the research purpose.

Central to this study was the child or adolescent PIC survivor and so approaches adopted to gather and analyse data needed to focus on harnessing their voice. From the outset of the study, I proposed that this would be achieved by engaging them directly and exploring their accounts, as well as those identified as significant within their lives. Furthermore, I aspired to explore the context and sequence of reports in an attempt to understand how the phenomenon was constructed over time. These aspirations appeared to align broadly to a narrative approach as stories are familiar, they reveal truths about human experience (Frank, 1995; Bailey and Tilley, 2002; Frank, 2002; Riessman, 2008) and allow for temporal experiences and events to be explored (Denzin and Lincoln, 2008).

Narrative approaches have been applied in a range of disciplines including linguistics, psychology, health, sociology and anthropology, resulting in a range of definitions and uses (Bamberg, 2012). Narrative approaches include: research

strategies, data collection methods, analytical techniques, and therapeutic approaches (Frank, 1995; Wells, 2011), which can vary in focus from life and oral histories, (auto)biographical, and performances. For this study the narrative approach provided a platform that framed and guided the data gathering encounter and first stage of analysis. A narrative approach congruent with the philosophical orientation of this study (outlined in section 3.3.2, page 59) was adopted that did not seek historical accuracy, but instead focused on the meanings constructed, and reconstructed, in participants' stories (Polkinghorne, 1988; Riessman, 2008). The ways in which the narrative approach was embedded within the case study design will be expounded within the subsequent sections in this chapter.

3.4   Research Methods: a flexible 'tool-box' approach

This study aimed to gain participation from PIC survivors that had previously been excluded from research in this field. Methods used had to be suitable for children that varied in chronological age as well as developmental, cognitive and physical ability.
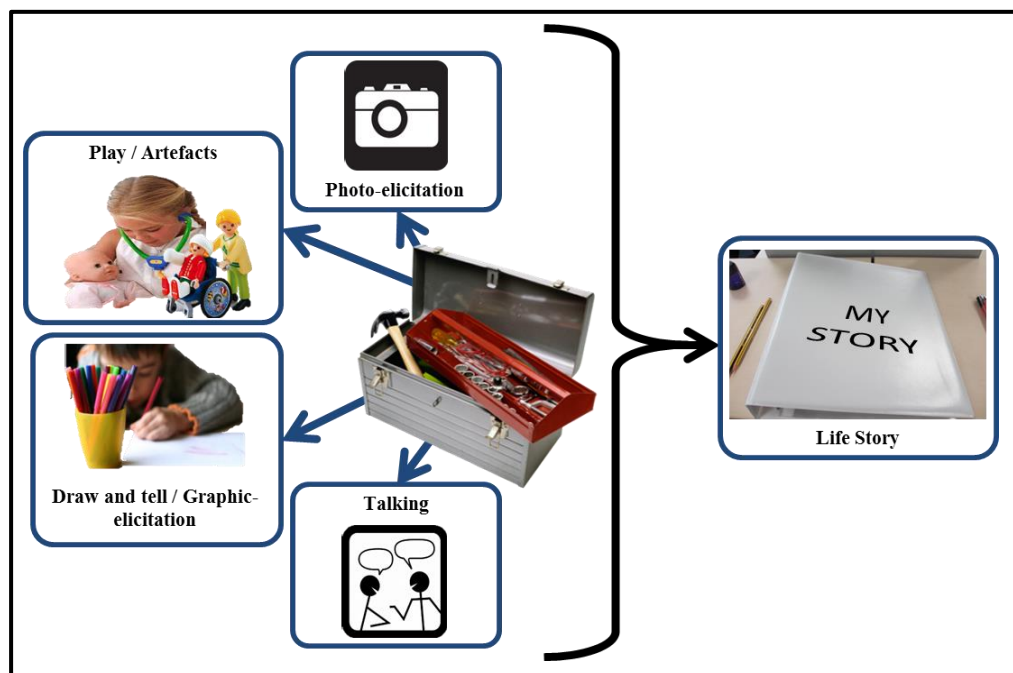
Figure 10: The 'tool-box' of methods used

Multiple methods are reported to provide a flexible approach for children to communicate their stories, experiences, and feelings in their preferred way (Crivello et al., 2009; White, Bushin, Carpena-Mendez et al., 2010). Furthermore,

congruent with case study research, the collection of data via multiple methods is recognised as providing a greater platform to explore phenomena (Stake, 1995; Yin, 2009). Therefore, a range of qualitative data collection methods was utilised (shown in Figure 10) that have been identified as familiar and interesting to children and adolescents.

Data collection methods were selected from studies within the literature that had effectively used child-centred, collaborative research approaches to explore children's experiences and lives. Two predominant groups of techniques were prevalent in the literature and included: talking such as conversations, interviews and focus groups; (Murphy et al., 1998; Birbeck and Drummond, 2005; Paton, Crouch and Camic, 2009) and art-based methods such as drawings, paintings, photography and collage (Coad, 2007; Bagnoli, 2009; Holliday, Harrison and McLeod, 2009; Driessnack and Furukawa, 2012; Carter and Ford, 2013).

In addition to the literature, children and families were involved in the study development. They were engaged through face-to-face meetings, via postal mail and over the telephone in order to elicit feedback on the proposed methods to be used. Overall, positive feedback was elicited from all children and adolescents, with flexibility and choice being fundamental. It resulted in a range of art-based techniques in conjunction with interviews being utilised (Figure 10).

3.4.1 Talking: a responsive interviewing approach

Talking or interviews are an essential approach to collecting data in case study research (Stake, 1994, 1995). Despite concerns with power dynamics of undertaking interviews with children (Bethlehem, Griffin and Camfield, 2009), there continues to be prolific and effective use in child health research, predominantly with children from six years of age (Huang, O'Connor, Ke et al., 2014).

A number of approaches to interviewing have been used in narrative research, such as that used in biographic narrative interpretive method (Wengraf, 2001). However, these have been predominantly applied to linguistically and cognitively competent populations, such as adults. Due to the diversity of the proposed sample of PIC survivors, and their significant others, a responsive interviewing

technique was adopted (Rubin and Rubin, 2005). Similar to how Riessman (2008) conceptualises the narrative approach, responsive interviewing recognises the participant-researcher as generating the story told. Furthermore, it focuses on the depth of understanding and the researcher's role in actively listening and adapting lines of inquiry from the unfolding story (Rubin and Rubin, 2005).

Interviewing children can be problematic. Practical challenges of undertaking interviews in chaotic environments (Coad, Gibson, Horstman et al., 2014) and threats to participant-researcher parity have been reported (Irwin and Johnson, 2005). Adopting an interview technique where the researcher is integral to the data collected can heighten issues of power as the researcher can influence how participants respond (Faux, Walsh and Deatrick, 1988; Anderson and Balandin, 2011). I attempted to address this potential challenge by encouraging the participants to make choices and decisions about how they constructed their story (Lansdown, 2005). For example, they chose where they wanted to tell their story and what medium they wanted to tell it through: I also respected them if they did not want to discuss certain experiences.

A broad topic schedule (Appendix A) was used to assist me in the exploration of abstract topics such as thoughts, feelings and meanings. These topics were not structured questions but just words that allowed me to tailor to the participant's language, cognitive and developmental ability.

3.4.2   Art-based and visual approaches

In conjunction with responsive interviewing technique, art-based and visual approaches were also used. Art and visual methods such as photographs, drawings and artefacts have been suggested to act as a symbolic language (Boyden and Ennew, 1997; Prosser, 1998) useful when accessing experiences, views, and perceptions (Coad, 2007). However, they remain underutilised in child health research (Driessnack and Furukawa, 2012) despite being extensively advocated for use in research with children (Boyden and Ennew, 1997; Prosser, 1998; Coad, 2007; Carter and Ford, 2013). The application of art-based and visual approaches in this study was useful due to: (1) the potentially sensitive nature of the phenomena under investigation, and (2) the varying cognitive and developmental level of PIC survivors. These approaches have been identified as facilitators in the

exploration of sensitive issues with children, such as fears and feelings, as they can be a safe and fun medium (Hill, Laybourn and Borland, 1996). Cognitive processing of visual information is easier than verbal or audio (Wickenden and Kembhavi-Tam, 2014). Art-based and visual approaches are recognised as suitable for all children irrespective of age and stage of cognitive development (Kirby, 1999).

Graphic elicitation

Drawings and other graphics, such as collage, have been used as an open-ended approach to elicit children's voices (James and Prout, 1997; Herth, 1998; Jolley, Fenn and Jones, 2004; Bethlehem et al., 2009; Campbell, Skovdal, Mupambireyi et al., 2010) and to explore their individual identities and social worlds (Driessnack, 2006; Coad, 2007; Pelander, Lehtonen and Leino-Kilpi, 2007; Driessnack and Furukawa, 2012). This demonstrates their appropriateness as a data collection method in this study.

Drawings were used to explore the participant's self, their emotions, and their social world by providing a platform for an accompanying explanation or story (Carter and Ford, 2013). Both 'draw and write', as a storied approach, and 'draw and tell', as a narrative approach, were used as they transfer the focus of the drawing technique from aesthetics to the participant's interpretation (Driessnack and Furukawa, 2012; Carter and Ford, 2013). Specifically 'self-portrait' and 'time-lining', which are participatory graphic elicitation techniques, were used (Bagnoli, 2004, 2009). Both techniques are reported to facilitate participants conveying concurrent temporal experiences, which is particularly useful for longitudinal research as changes can be observed (Bagnoli, 2009). Although Bagnoli (2004, 2009) uses these techniques to explore emigration identities of young people, the approach has similarities with techniques used by clinical psychology and social work to explore evocative issues with children.

In this study the techniques were used as an 'icebreaker' at the start of the data collection visit by asking the child to "draw a picture of themselves at this moment in time" and "draw a timeline of the important things that have happened in your life". I would then use these drawings with the responsive interviewing technique to construct their stories.

Photography and Photo-Elicitation

Photography is an art-based technique that has been reported to truly engage children (Coad, 2007; Driessnack and Furukawa, 2012). It is an approach that allows the researcher to view the world through the participants' eyes (Coad, 2007), providing in-depth knowledge into a moment in time (Banks, 2001). Photographs can capture diverse content such as individuals, objects, other people, or the environment (Driessnack and Furukawa, 2012). However, there is diverse application of photography in research, with photographs used as factual pieces of evidence as well as sources to elicit interpreted meaning (Close, 2007). The latter approach, termed photo-elicitation (Coad, 2007; Croghan, Griffin, Hunter et al., 2008) or photo-voice (Necheles, Chung, Hawes-Dawson et al., 2007), appeared most congruent with the aims and orientation of this study. This approach allows the researcher to bridge the psychological and physical worlds as photographs are used to discuss, evoke and explore participants' feelings, experiences and stories (Hurworth, 2003).

Each PIC survivor was given a digital camera to keep during the data collection phase. This allowed for the generation of data outside of the participant-researcher interaction. I had a portable printer that I would bring to visits and participants could select and print photographs that they had taken. These photographs were used as platforms to discuss experiences and events during the interviews.

Artefacts

Artefacts and props have been used in research with children, including masks, puppets or dolls, to facilitate the communication of experiences, views, and needs. A reported benefit of using artefacts is that it allows participants to be slightly removed from articulating emotionally-laden events (Driessnack and Furukawa, 2012). Therefore, artefacts were brought to the interview encounter by the participant and were used in a similar way to the graphic- and photo-elicitation approaches as a platform to share their story.

3.4.3   Bringing it all together: a life story book

In order to uphold the collaborative ethos it was fundamental that participants had ownership and control in constructing their stories. Due to the longitudinal nature

of this study, a framework was used to provide participants with the opportunity to collate, arrange and present their story in a familiar and flexible format. Life story work has been used extensively in social care to facilitate communicating complex and emotive information with children who have encountered adverse events such as abuse or adoption. More recently the method has been adopted into healthcare practice, specifically healthcare of the older person (McKeown, Clarke and Repper, 2006; Wills and Day, 2008), and as a research tool with children (Anderson and Balandin, 2011). By utilising a life story approach in this study, the PIC survivors were able to tell their story through a participant-focused medium adaptable to their potentially evolving participatory capacity. Moreover, the organisation of thoughts, themes and concepts within a chronological order can assist in children comprehending space and time recovery.

In this study the life story approach was applied by providing each PIC survivor with an A4 lever arch file to collect their story, e.g. drawings, paintings, photos. PIC survivors remained the owner of their 'story' and the contents within it. This ensures that participants decide what artefacts are available to the researcher and they remain the property of the child (Yin, 2009). It also provides opportunity for participants to construct their story as it evolves, outside the time points of researcher-participant contact; thus acting as a prompt during the researcher-participant interview. However, a criticism of using this framework is that it constrains stories to chronological sequence. Therefore, it was important to stress its use was optional to avoid the participant's story being constrained.

3.5   Study procedures

3.5.1   Ethical review and study governance

The study was conducted in accordance with the ethical principles originating from the Declaration of Helsinki, (World Medical Association, 2008); principles of Good Clinical Practice (ICH GCP), and the Research Governance Framework for Health and Social care (Department of Health, 2005). This study was subject to review by a National Health Service (NHS) Research Ethics Committee (REC) with full approval received from East Midlands REC (ref: Derby 1, 12/EM/0230). A site-specific assessment was undertaken and approvals granted by the NHS Trust Research and Innovation Department, where the participants were recruited.

A study steering group was formed from the outset of the project. It was composed of a consultant paediatric intensivist, consultant paediatrician, a paediatric clinical psychologist, a school nurse, an assistant head teacher/special education needs coordinator (primary), a parent of a PICU survivor, and two children who had been hospitalised. The steering group provided specific guidance in relation to recruitment, ethical and safeguarding processes.

3.5.2 Study setting and sampling strategy

The study was conducted with survivors of an acute life-threatening critical illness from a single PICU in the East Midlands, United Kingdom. It is one of 26 NHS PICUs in England that provides up to level 4[19] intensive care services to children (NHS Executive, 1997), from birth to 18 years, from the geographical catchment of the North of the East Midlands[20]. The PICU has approximately 350 admissions per annum (PICANet, 2011) and is situated in a large children's hospital that provides a number of regional and supra-regional specialist services. However, children and adolescents that require critical care for primary cardiac or hepatic conditions are referred to other centres.

Sampling

In qualitative research there are many different forms of sampling available and debates about the required sample size (Coyne, 1997; Murphy et al., 1998). It is recognised that the sampling strategy employed and size of sample should be governed by the methodology and topic under investigation (Higginbottom, 2004). The focus of this qualitative study was to gain an in-depth exploration and understanding (Ritchie, Lewis and Elam, 2003). Previous research in the field (outlined in Chapter two, page 27) has focused on homogeneous samples through selecting specific disease groups or excluding children with certain attributes. This has resulted in studies that do not recognise the heterogeneity of the PICU populace. Therefore this study sought participation from PIC survivors who

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19 Defined by Paediatric Intensive Care Society standards (2010, Appendix p.5) as patients requiring 'intensive supervision at all times' and 'needs additional complex therapeutic procedures and nursing'.

20 Paediatric critical care services are configured on a national system, outlined by NHS Executive (1997), it is possible for children and adolescents from anywhere in the United Kingdom to be admitted if their local PICU does not have adequate provision.

varied in age, ability, and outcome, as well as time since PICU discharge. When considering the sample size, Morse (2000) indicates that there are five factors that should be postulated. These were considered in relation to this study and are outlined in Table 6.

Factor	Consideration for this study
The scope of the study	• Focus on psychosocial well-being • Children and adolescents only • After acute life threatening critical illness
Nature of the topic	• Complex as involves individual, family and society • Difficult to obtain information
Quality of Data	• Multiple methods utilised • Need to gain a comprehensive and rich picture • Multiple sources
Study design	• Case study • Longitudinal
The use of shadowed data	• Was utilised to identify how the experience of the participant integrates, is influenced or affected by others in case

Table 6: Considerations for sample size using Morse (2000) five factors

It was evident that a large amount of data would be collected, at different time points, and from different sources. Morse (2000) suggests that the greater the useable data elicited, the fewer participants are needed. Taking this into consideration, despite previous studies exploring as few as five cases (Siebes, Ketelaar, Gorter et al., 2007), a maximum of 20 cases was initially sought.

Theoretical and chain-referral sampling

In order to identify and recruit the proposed 20 cases, a sequential sampling strategy was employed which involved both theoretical sampling to select PIC survivors, and chain-referral sampling to select significant others within each case study (outlined in Figure 11).

Theoretical sampling is defined by Emerson (1981, p. 360) as an approach, '…in which new observations are selected to pursue analytically relevant distinctions rather than establish the frequency or distribution of phenomena'. This sampling approach upholds the purpose of collective case studies whereby case variation is sought (Stake, 1995).
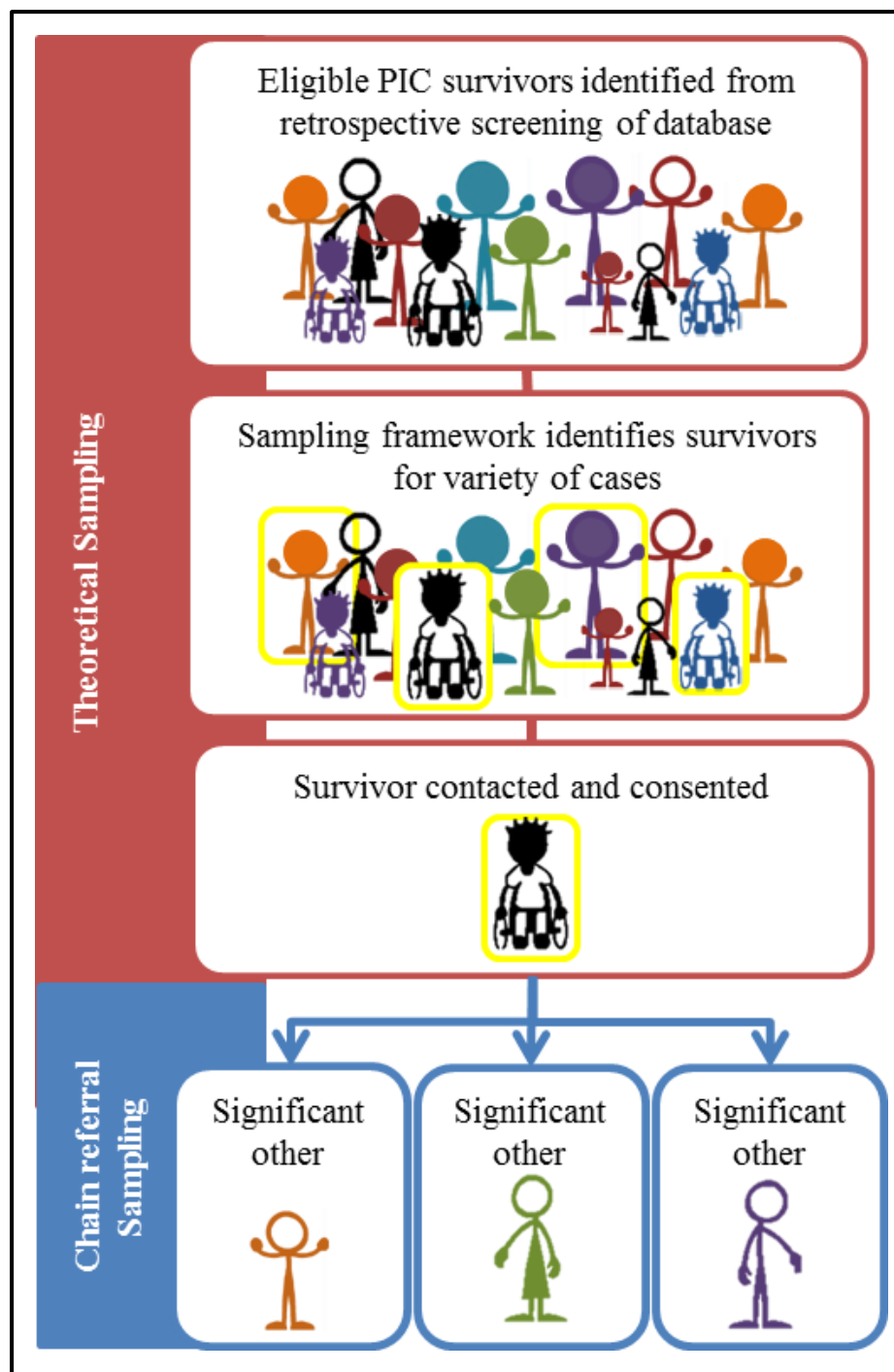
Figure 11: A diagram representing how the sequential sampling strategies were employed

Therefore, in addition to criteria that identified participants according to the scope and purpose of the study (Table 7), a theoretical sampling framework was also devised.

Inclusion criteria	Rationale
1. Children and adolescents aged between 6 - 18 years	• Although childhood has been defined to commence at 3 years, the methods to collect data, such as interviews, have been predominantly used with children aged 6 years and above (Huang et al., 2014) • 18 years is the maximum age to be admitted to PICU
2. Survived emergency admission to PICU	• Represents the modality of admission for the majority (≥70%) of children and adolescents admitted to UK PICU • Used to indicate the severity of critical illness (e.g. life threatening) (Bronner et al., 2008a)
3. Invasively intubated and ventilated for at least 24 hours whilst on PICU	• Used as an indicator of critical illness (Bronner et al., 2008a) • Differentiates children and adolescents admitted to PICU for monitoring or high dependency care.
4. Three to 12 months since discharge from PICU	• Time from contact to enrolment to enable capturing ≥ six months from PICU discharge • To enable the exploration of a range of experiences and time-points since PICU discharge
5. Consents/assents to participate in study	• To comply with the Research Governance Framework for Health and Social Care (Department of Health, 2005)
Exclusion criteria	**Rationale**
1. Unable to fulfil inclusion criteria	• Identified as outside the scope of the study • Would not comply with the Research Governance Framework for Health and Social Care (incl. criteria 5).
2. PICU admission due to child protection issues	• Concerns relating to researcher safety • Identified as a different patient group
3. On an active end of life care pathway	• Identified as a different patient group (Rees et al., 2004) which may conceptualise the notion of survival differently
4. Non-English speaking	• Stipulation from NHS REC as unable to translate study materials into different languages due to limited study resources

Table 7. Eligibility criteria and rationale for the selection of PIC survivors

The purpose of a sampling framework was to achieve variation of the PIC survivors identified as eligible for participation. In relation to this study, variation of reason for admission to PICU, as defined by the International Classification of

Diseases 10 (World Health Organisation, 2005), and time since PICU discharge was sought (outlined in Table 8).

Condition (reason for PIC admission)	Time since discharge from PIC	
	3-6 months	7-12 months
Circulatory system	1 Participant	1 Participant
Digestive system	1 Participant	1 Participant
Genitourinary system	1 Participant	1 Participant
Haematological	1 Participant	1 Participant
Infections	1 Participant	1 Participant
Injury/poisonings	1 Participant	1 Participant
Metabolic disorders	1 Participant	1 Participant
Neoplasms	1 Participant	1 Participant
Neurological	1 Participant	1 Participant
Respiratory system	1 Participant	1 Participant

Table 8: Theoretical sampling framework

However, theoretical sampling was not appropriate for selecting the significant others within the case. Significant others were selected on the basis of whether the PIC survivor perceived them to be an important person in their life. From the study outset these were an undefined and unknown population. Therefore, a suitable sampling approach for hidden populations is chain-referral sampling (Faugier and Sargeant, 1997). This approach aligns to the child-centred ethos, as participants are referred or nominated by existing study participants (Salganik and Heckathorn, 2004) who, in this study, are PIC survivors.

3.5.3   Screening and recruitment

To conform with NHS research governance (Department of Health, 2005) and the Data Protection Act (Data Protection Act, 1998), written consent was required prior to the researcher gaining access to patient data. Retrospective screening of the PICU admission database, using eligibility criteria (Table 7), was undertaken by the PICU clinical team. Of those identified eligible the theoretical sampling framework was then applied.

To overcome perceived issues of coercion, an 'opting in' approach was used (Hedgecoe, 2008; The Heath Research Authority, 2013) where initial contact to participate was conducted by the clinical team via postal mail. Opting in has been

reported to yield significantly lower response rates than 'opting out' approaches (Hewison and Haines, 2006). Therefore, reminders were used as a strategy to increase the number of respondents (Nakash, Hutton, Jørstad-Stein et al., 2006; Mapstone, Elbourne and Roberts, 2007). Although telephone reminders were the favoured approach, these were perceived by the REC as coercive and so disallowed. Subsequently postal reminders were used if no response had been received after 14 days from posting.

3.5.4   Consent and assent

Conducting research with children involves particular challenges in relation to gaining consent whilst upholding their autonomy. Concerns relating to children's understanding, due to evolving developmental ability, have resulted in age restrictions being imposed on who can consent (Morrow and Richards, 1996). For those children aged 15 years and younger, the consenting process for involvement in research has relied upon adults, such as parents, to represent their views. However, children have been reported to feel pressurised to participate if their parents have already consented (Green and Thorogood, 2009). In this study it was a recognised as a child's right to be actively involved and share the decision to participate (Morrow and Richards, 1996) as this can enhance well-being and perceived self-efficacy (Weithorn and Sherer, 1994). This was achieved through study information leaflets and conducting a study information visit.

Study information

Primarily, a range of written, visual and verbal methods (Appendix B) was used during the consenting process to facilitate participant understanding of the study (Polit and Beck, 2008). This information was designed and reviewed by children and families involved in the study development phase. This approval from children and families is advocated to ensure information is comprehensive to enable potential participants to make an informed choice over whether to consent to or decline participation (Polit and Beck, 2014). Feedback highlighted ambiguous terminology, issues with font size and document length, and the need to use more colours, which were all included in the final information sheets.

PIC survivor: study information visit

Study information sheets were sent to eligible PIC survivors and their parent or legal guardian with the invitation letter from the clinical team. Respondents that requested more information about the study were contacted by telephone. A pro-forma was used during this telephone call to structure, prompt and provide a written record of the information discussed that included: confirming their continued interest in the study; arranging a face-to-face information visit at a convenient time and location; checking their consent for a lone male researcher to undertake the visit; and providing an opportunity to ask any questions.

For convenience the dates, times and location of the study visits were selected by participants. It was anticipated that the visits would occur in their own home, during evenings or at weekends as PIC survivors would be in full-time education or employment. Participants also determined who else they wanted present during the visit. To ensure both PIC survivors and their parent or legal guardian could make an informed decision about participation, details of the study were discussed in depth at an information visit. This visit included:

• Emphasising that entry to the study was entirely voluntary and that any ongoing treatment and care would not be affected by their decision,

• Explaining, if they chose to participate, that they could withdraw at any time,

• Ensuring that the eligible participant and parent had sufficient time to consider participating or not (up to 48 hours),

• Providing assurances in relation to the confidentiality and anonymity of the data collected,

• Making eligible participants aware that, should they withdraw consent, the data collected (to date) could not be erased and might still be used in the final analysis,

• Giving eligible participants and their family opportunity to ask the researcher questions they had concerning study participation.

I used a schedule (Appendix C) as an aide-memoire to keep the visit centred on the PIC survivor. Each visit began with my introducing myself and explaining why I was doing the project (Image 1). The study information sheets were used as a visual platform to explore and discuss the research (Appendices A & B). 'Rachel's story' (Image 2), which had been developed during the user-involvement work, was used as an example of the different ways the toolbox of methods could be used to tell their story.
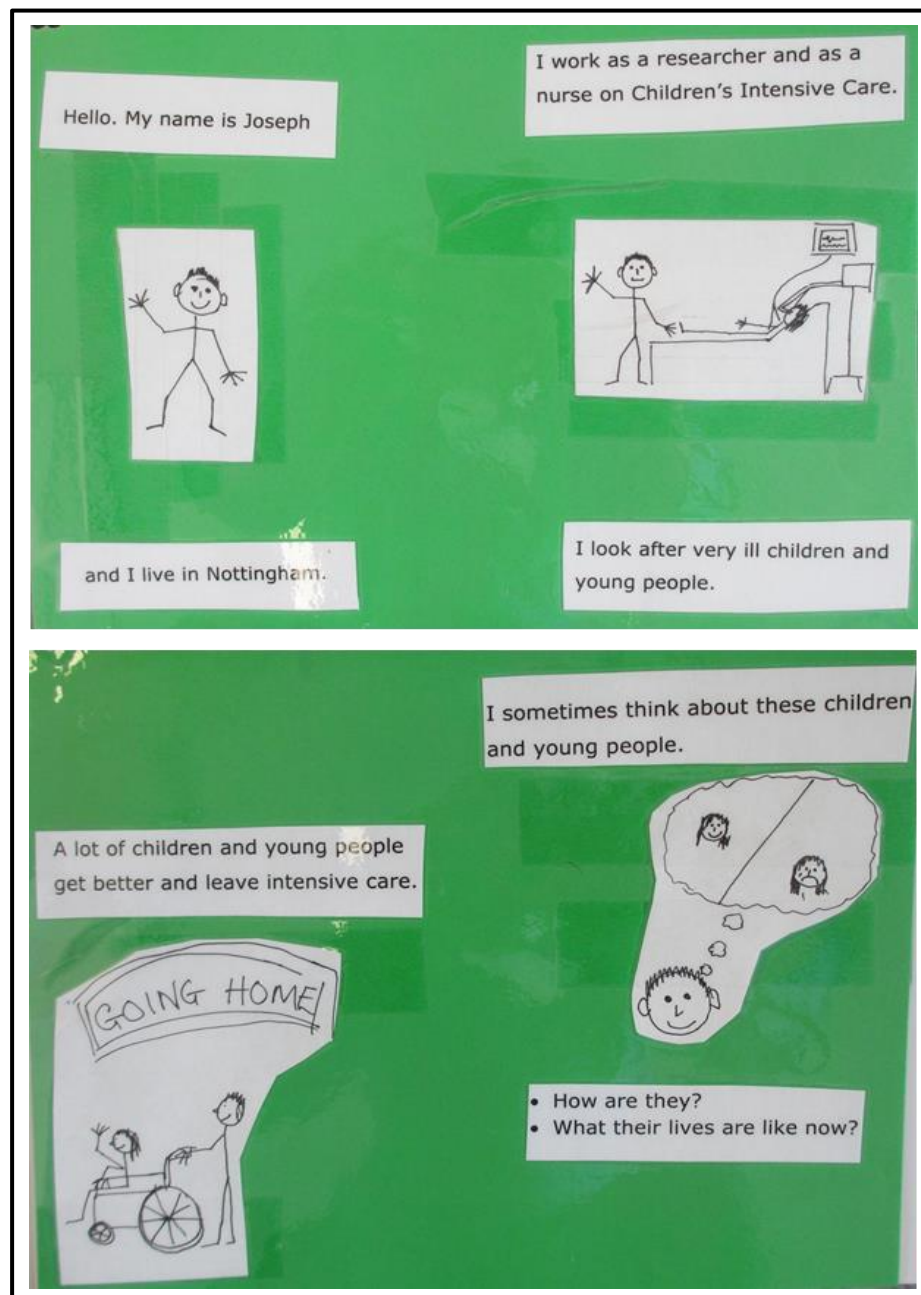
Image 1: The researcher's story

Image 2: Rachel's story

However, I stressed it was up to the child what 'tools' they used and that they were not mandated to undertake any of the activities. During the initial visit I encouraged the children to interact with the cameras, printer and art equipment that would be used in the study. Specifically, the camera and portable printer provoked much excitement and enthusiasm with the majority of children and any siblings present. I provided each child with a pack of stationery (paper, felt tips, pens, and folder) and a digital camera to use for the duration of the study and encouraged them to collect information about their story in between my visits, although I did stress this was optional and 'not homework'.

Information for significant others

A letter of invitation and information sheet (Appendix D) were provided to significant others by the PIC survivor. This requested that the significant other, or their parent/legal guardian, should contact the researcher directly if they were interested in participating in the study. For those who responded, a suitable time and place for an interview were arranged and any questions they had about the study answered.

Consent and assent process

In line with the Research Governance Framework for Health and Social Care (Department of Health, 2005), written informed consent was obtained from all study participants. For PIC survivors, consent was obtained following the information visit. However, for significant others consent was obtained prior to the interview being conducted. Similar to the study information visit for the PIC survivors, the visual platforms to discuss the study were employed and opportunity to ask questions was provided.

Informed consent was completed by all participants before they entered the study. For those participants aged less than 16 years, parental consent was obtained. The child's confirmation to participate in the study was then sought through an ethical and empowered assent process (Bray, 2007). Assent involved ensuring the child understood:

- the voluntary nature of their participation (Hurley and Underwood, 2002),

- the risks and benefits of participation (Leikin, 1993),

- they were under no undue pressure to comply,

- the lack of objection did not signal assent (Diekema, 2003).

3.5.5 Interview process

Following consent, each case study was explored longitudinally over a six-month period, involving a minimum of three PIC survivor face-to-face visits. As data were collected at a number of time points, each visit began by reconfirming the participant's willingness to be involved in the study. This was deemed important as I recognised that children may have felt obliged to continue in the study due to perceived parental or researcher expectations.

Developing ground rules

Each interview began by engaging the participant in developing ground rules for the encounter that included statements like 'you don't have to answer any questions' and 'please tell me if you want to stop or are bored'. The participants could add anything that they felt important. During this part of the interview I also felt it important to explain that confidentiality would be maintained and I would respect the privacy of the subject and their information (Green and Thorogood, 2009). I outlined that our discussions were confidential and all identifiable details would be removed from our conversations. I also made it clear that as a registered professional with the Nursing and Midwifery Council (UK, first level), I was bound by a code of professional conduct. Therefore, I continued to have a professional obligation that if, at any time, they, their parent, or significant other disclosed information that related to safeguarding or child protection I would have to share that information with other agencies. For the PIC survivors these ground rules were formalised in their life story folder, which included rules on who could access their story.

Audio recording

With the participants' agreement the interview was audio-recorded using a digital voice recorder. In an attempt to provide the child participants with choice, the recorder was handed to them to start and stop as they desired.

Ethical considerations: safety of participants and the researcher

All visits were conducted with the parent present, or co-located in the house. This was a precautionary measure to ensure the safety of the participant and of myself, as I conducted all visits alone.

Due to the in-depth, longitudinal, and exploratory nature of this study, I was aware that relationships, and a level of dependency, may develop between the participants and myself. Therefore, following the final interview, a debrief was conducted to provide an opportunity for participants to reflect on their involvement in the study. This also allowed me to provide signposting to support if required. Parents and family members were encouraged to participate in this debrief session to share their views and opinions about the study and to offer support to the child.

To ensure I had opportunity to reflect and learn from my experiences and research practice, I received clinical supervision during the data collection phase. Participant confidentiality and anonymity were maintained during these sessions, conducted by a registered clinical psychologist.

Ethical considerations: power and sensitive topics

From the outset it was recognised that participants might have ongoing psychological sequalae and the stories told during interviews might provoke negative emotions. The longitudinal and in-depth nature of the study provided opportunities for any issues, feelings and emotions to be discussed in a sensitive and supportive manner. This reciprocal dialogue between participants and researcher allowed for signposting to the appropriate services, if required. Furthermore, the study steering group (outlined in section 3.5.1, page 71) had the expertise of a paediatric clinical psychologist who could provide advice and support to the researcher if any issues did arise.

A process (Figure 12) was also devised with the study steering group and user-involvement work to guide the researcher in responding if a participant became distressed during a visit.
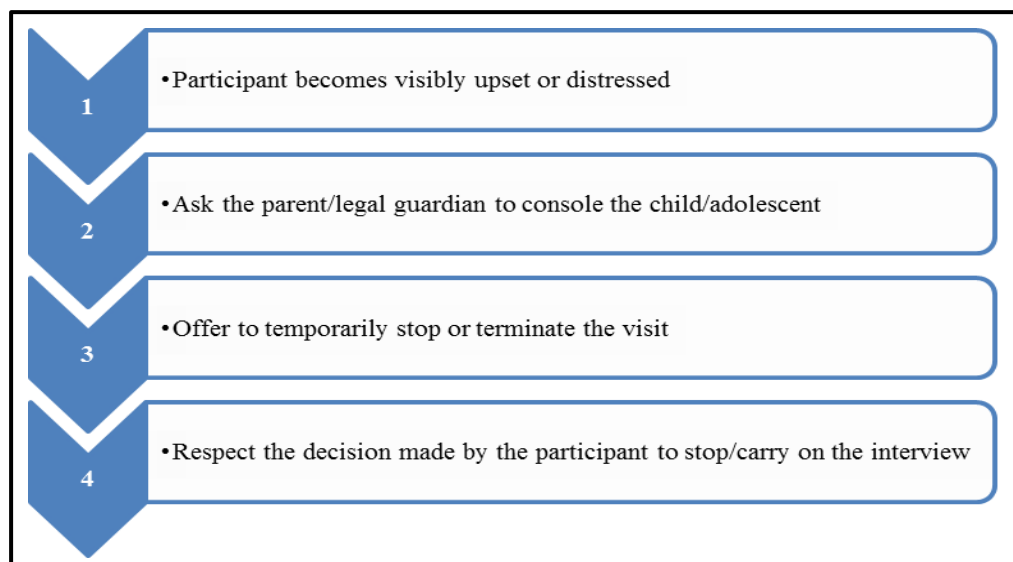
Figure 12: Process for dealing with participant distress during the interview

3.5.6 Data analysis

Data management and transcription

Throughout the study I protected the rights of the participants' privacy by adhering to the Data Protection Act (1998). All electronic audio and visual data were uploaded onto a password-protected university server and source data, such as field notes, were stored in a locked cabinet in a locked room. Access was limited to myself, my PhD supervisors, and any relevant regulatory authorities.

The interview audio files were transcribed verbatim and visual images, such as drawings and photographs, were inserted into the transcript at the point of reference. I conducted all the transcribing for the interviews with the PIC survivors and child significant others in the study. Due to the large amount of audio data collected, an external transcription company[21] was used to transcribe the adult significant other interviews. Audio data were uploaded to the transcription service in an encrypted file format via their website (128 bit SSL secured) and transcripts were returned via email in a password protected file format. For all participant interviews, I undertook a process of quality checking where I listened to and read the transcript for accuracy, as well as removing all identifiable information. Following transcription, these were then sent to each

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[21] Transcriptionists signed a confidentiality agreement prior to undertaking any of the work.

participant as it remained part of their property and it also gave them opportunity to make any changes if wanted (as outlined by Hagens, Dobrow and Chafe, 2009).

Analysis: combining abductive and inductive logics

Blaikie (2007) suggests that logics of inquiry constitute different ways to address research problems. He proposes four possible strategies (Table 9) that differ in relation to logic, utilisation of theories and concepts, and the status of the research products as underpinning drivers to decide on the most appropriate analysis plan.

	Inductive	Deductive	Abductive	Retroductive
Aim	Establish descriptions of characteristics and patterns.	Test theories and eliminate false ones.	Describe and understand social life in terms of social actors' understanding and motives	Discover underlying mechanisms to explain observed regularities
Logic	Reasoning moves from singular statements to universal conclusion	Reasoning moves from universal statements or premises to singular conclusion	Moves from data description of phenomena to a hypothesis that accounts for the reliable data whilst seeking to explain relevant evidence.	A hypothetical model of an unknown mechanism or structure is constructed. Its existence is then attempted to be established through observation and experimentation
Start	Collect data on characteristics and/or patterns	Identify a regularity to be explained	Discover everyday lay concepts, meanings, and motives.	Document and model a regularity
Finish	Produce descriptions Relate to research questions	Construct a theory and deduce a hypothesis Test hypotheses by matching them with data	Produce a technical account from lay accounts Develop a theory to elaborate it iteratively	Describe the context and possible mechanisms Establish which mechanisms provide the best explanation in that context.

Table 9: An overview of the four research strategies[22]

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22 Adapted from Blaikie (2007) pp. 68, Table 3.1

This study aims to understand how PIC survivors construct long-term psychosocial well-being within the context of their lives, and how the phenomenon manifests across cases and contexts. To achieve this broad remit it was apparent that both abductive and inductive logics of inquiry needed to be employed to collect and analyse the data. Despite the four research strategies being constructed based on incompatible logics, practically it is necessary and possible to combine them through sequential or integrated strategies (Blaikie, 2007). Therefore, a sequential abductive-inductive approach to data analysis was employed (Figure 13) that built from the individual to the collective.
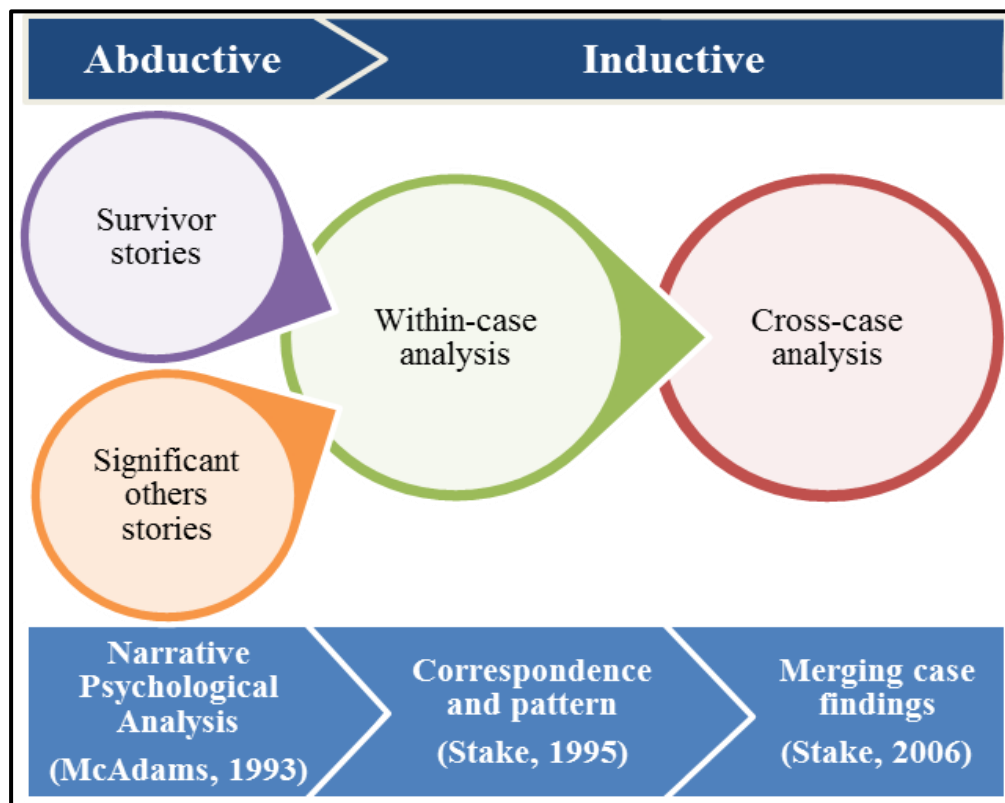
Figure 13: Schematic representation of the data analysis plan and their logics

Abductive analytical approach

The first stage of analysis was underpinned by an abductive logic, defined in Table 9, that involves accessing a participant's individual and social worlds through their accounts (Fox, 1988). Traditionally, this is achieved through language - however, in this study, accounts and meanings, through language and visual imagery, were interpreted to generate understanding.

To maintain the temporality and situationality of the storied experiences, a narrative method of analysis was used (Creswell, 2007). Narrative analysis involves interpretation of language, images and artefacts within their social, cultural, and historical context (Riessman, 2001, 2008). However, no consensus is evident within the literature as to a single narrative analytical approach to be used. Therefore, as a novice, I trialled the process of analysis on one case study using the technique explicated by Rosenthal (1993). It became evident that this approach was too broad and resulted in an unfocused and relatively superficial interpretation of the participants' stories. Further reading of key texts in the field of narrative research (including Frank, 1995; Riessman, 2008), as well as discussions with narrative researchers within the department led me to search for a narrative analytical approach which was more focused on analysing the self and social worlds within stories.

The narrative psychological analysis approach devised by McAdams (1993) and subsequently developed by Crossley (2000) is an holistic-content analytical approach. The technique is based on the assumption that an insight into an individual's psychological and social worlds can be gained through understanding the content and complexity of meanings produced in interview situations (Crossley, 2000, p. 88). From an ontological perspective this form of analysis mediates between constructionist and realism (Smith, 1995). Although a realist position did not appear congruent with the philosophical tenets of this study, on further exploration this approach perceived reality as a product of one's own creation; each individual sees and interprets the world and their experiences through personal belief systems (Crossley, 2000). The analytical process involved a five stage process that is summarised in Table 10, below.

To retain the significance of each participant's stories, analysis was conducted on data from each participant within each case study. Narrative psychological analysis was conducted by hand with each interview transcript. A wide margin was placed on the right side of the transcript for classifying the content into the five components of a life story, writing notes, comments and personal impressions, and coding the emerging narrative themes and genres. This was undertaken with each interview transcript (e.g. PIC survivor n=3, significant other n=1). Stages 3

and 4 of the narrative psychological analysis approach were mapped under each of the six components of a life story into a table.

Stage	Description of processes
1. Reading and familiarising	• This preliminary stage, also referred to as 'naïve reading', involved repeatedly reading through the whole transcript (about five or six times) in order to familiarise oneself with the material, enabling a general gist of emerging and significant themes (Crossley, 2000) • This process is reported to allow the researcher to immerse himself in the content and take note of the atmosphere of the interview.
2. Identifying important concepts to look for.	• This step involves establishing the principal elements of the 'personal narrative'. Narrative analysis takes note of the detail within the text, as well as emerging themes. • Whilst much of this attention to detail has been developed through conversation analysis (the pauses and silences), the specific use of language will be equally as important. (Crossley, 2000)
3. Identifying 'narrative tone'.	• McAdams (1993, 1995) identifies narrative tone as the most pervasive feature of biographical narratives. Tone is conveyed in both the content and the form of narratives. (Crossley, 2000) • This step focuses on what made up the story (e.g. events) and how this is portrayed (e.g. optimism / sorrow / despair).
4. Identifying 'imagery' and 'themes'.	• This step involves identifying imagery (such as metaphors, descriptions and actual images) and dominant themes that demonstrate the significance and mechanisms that surround important events reported in the narrative. • These are mapped in relation to six aspects of the narrative: life chapters; key events; significant people; future script; current problems; and personal ideology. (Crossley, 2000)
5. Weaving it all together.	• The final step is the 're-storying' of the participant's narrative. • This stage re-integrates the components of the holistic-content analysis of verbal and visual stories into a coherent story. • This is more than description and development of themes as found in other qualitative approaches (Ollerenshaw and Creswell, 2002) as "re-storying" from original raw data involves: co-constructing the data, transcribing, reading the transcript, analysing the story to understand the lived experiences, and then retelling the story (Clandinin and Connelly, 2000; Ollerenshaw and Creswell, 2002).

Table 10: Stages of Narrative Psychological Analysis

This involved (Figure 14) populating the table with imagery, codes/themes generated from the analysis and excerpts from the transcripts to provide transparency to the reader. From this table (or tables for the PIC survivor), the re-storied account was generated and written in full for each participant.

Psychological narrative analysis (Stages 2-4)

1ˢᵗ Data collection visit

(December 2012, 13 months since critical illness)

Events	Imagery	Codes/Themes
Cohabiting - Moving between parents	Movement: 'we've got this house in LOCATION 2,...there's another house in LOCATION 1,...I live there for during the week and then I come back here because my mum is living here. So I come back here for my weekend and then go back to LOCATION 1.' (Ln 25-29, p.1) 'We moved in June this year.' (Ln 94, p. 3)	• Geographical movement to reunite with mother
Unknown event - My father's death	'my real dad, he died when I was only three months, I don't really know him.' (Ln 121-122, p.4)	• Unknown father

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Events	Imagery	Codes/Themes
Transitioning - Moving from Africa to the UK	'I'm from Africa, Zimbabwe.' (Ln 134-136, p. 4)...I come here 2010 I think, 10, I can't remember, 10 or 9, I forgot... my mum wanted me to come here and live with her, because she was here for longer.' (Ln 142-151, p.4)	• Raised in different country/culture • Maternal separation Vs. maternal desire for reunification • Immigration
Trying to be heard - Knowing something was wrong with me but no one listened	'...I went in Year 9... I just feel weak... my friend would say oh Katherine what's wrong with you? ...I don't know ... I told my mum she thinks I didn't brush my teeth very well...I didn't feel well that day and I just feel weak, ...went to the loo and my wee, all the wee was all blood. I told my mum...she was like it's just blood....on my skin it was coming...you can see blood through my skin, and my throat... I just feel something block my throat... I show my aunt and my uncle,...I showed my mum, that's when she take it serious from then...I couldn't speak properly' (Ln 196-223, p. 6)	• Recognising a change: concern from peer • Requiring confirmation of concern from family • Symptom disregard (maternal) • Muted by condition and others • Self-perseverance/persistent to be heard
Diagnosis and treatment – bodily failure, hospitalisations, and interventions	'I went to the hospital...give me like three bags of blood and three bags of platelets because I had like, I didn't have blood and platelets in my body. ...they told me I had plastic anaemia which I didn't know what it was...I asked them what it was and they told me it was like when your bone marrow stop producing blood, so I need a new bone marrow transplant.' (Ln 224-274, p. 6-8)	• Lack of essential bodily components: Body failing • Unsure of what diagnosis meant: seeking understanding
Critical illness- infection and the	Critical illness, coma and near death: 'like five the same day I was shivering...I know if I start shivering it's like high temperature... I was shivering a lot... I felt so weak. I couldn't	• Awareness of physical deterioration Vs. amnesia of

Figure 14: Screenshot of an example narrative psychological analysis table

Inductive analytical approach: Within-cases

The next stage of analysis built on the findings from the narrative psychological analytical approach. The within-case analysis aimed to formulate context-bound descriptions of patterns between the survivor stories and the stories of significant others. This analysis employed an inductive, pattern-matching approach which has been advocated for use in case study research (Stake, 1995; Yin, 2009). This involved the dominant narrative themes and genres identified from the

descriptions, metaphors and imagery within each story being explored and compared.

This process began by reading the re-storied narratives of the participants within each case study and reviewing the findings from analysis tables. Findings were then compared and contrasted across participants within each case. A systematic and iterative process was employed that involved challenging, re-thinking, and re-sorting of the emerging findings that allowed for similar and divergent themes to be explored. This analysis was tabulated into theme, source and supporting excerpt that provided transparency in the conclusions made.

A report of the findings from within the case analysis was produced which provided a context-bound insight into the phenomena. This was combined with a contextual description of the case and the re-storied narratives of the survivors to formulate a comprehensive case study report.

Inductive analytical approach: Across stories and cases

Stake (2006) claims that a fundamental task in multiple-case research is to explore how the phenomenon differs in different contexts. He proposes that through 'categorical aggregation' of instances across-cases, assertions about the quintain as a whole can be made (Stake, 1995). Three 'tracks' for cross-case analysis have been proposed and are outlined in Table 11, below (Stake, 2006).

Track	Rationale for use	Strategy
I: Emphasising case findings	•Stake's preferred option •Maintains the case findings and context •Identified as the most difficult analytical option •Pertinent track when individual findings are more important than the quintain	•Sorting findings strips •Utility and prominence of cases •Focus on atypicality •Tentative assertions
II: Merging case findings	•Similar findings are merged whilst maintaining some context. •Pertinent track when understanding the quintain is more important than the individual cases •A theme is a central idea having importance related to its situation. It is at least somewhat context-bound, more local than universal. •Where some degree of contextual understanding is still desired	•Sorting and merging findings •Sorting and ranking findings- 'a lengthy list diminishes the importance of individual assertions' (p. 62) • 'Each assertion should have a single focus, an orientation for understanding the quintain, and evidence to support it' (p. 62)
III: Providing factors for analysis	•A much more quantitative method 'a factor, as used here, is a widely found, sometimes influential variable of interest well beyond its situation' (p. 64) •Context is lost	•Identify factors for each case. •Merging factors •Sorting and ranking factors

Table 11: Tracks for cross-case analysis and rationale for use[23]

The purpose of the cross-case analysis in this study was to build on the narrative and within-case analysis to explore inductively similarities and differences of the phenomena across cases. Therefore Track II was used as it is reported to provide an aggregate perspective of case findings whilst maintaining some context (Stake, 2006).

This stage of the analysis involved a data driven, iterative and inductive process of reading (and re-reading) the case reports, interrogating and revising the analysis to develop an holistic overview of the dominant findings across the cases. I took my interpretations of each instance, whether that of the survivors or whole cases, and compared across cases. Tables were developed that outlined the core findings for

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[23] Adapted from Stake (2006)

each survivor story whilst maintaining the context and situationality. These tables allowed themes, genres and relevant data from one story to be explored and compared against another, maintaining the transparency of the process and allowing for explanatory notes and comments to be documented. Typologies (classifications according to a general type) were then built across the cases to enable sub-groups to be delineated within general categories (Bryman and Burgess, 1994).

Decision not to use CAQDAS

Initially Computer Assisted Qualitative Data Analysis Software (CAQDAS) was used to conduct the narrative, within- and cross-case analysis. The NVivo 10^{TM} programme was used as it is advocated in managing multiple sources of data, aids transparency of analytical processes, and facilitates visualizing linkages within and across themes and stories (Welsh, 2002). However, attempts to use this computer programme resulted in the findings fitting the software as opposed to the software facilitating the analytical process. Due to the linear approach of the software, themes formulated appeared de-contextualised from the stories and steps of the analysis were hidden from the audit trail. CAQDAS guiding the researcher has been recognised as a potential problem within the literature (Seidel, 1991). Despite having undertaken specialist training on NVivo 10^{TM}, I opted to undertake the analysis by hand using tables on Word 2010^{TM}.

3.5.7   Quality in qualitative research: reflexivity and representation

The classification of quality in qualitative research contrasts greatly within the literature (King et al., 1994; Seale, 1999; Shadish et al., 2002; Golafshani, 2003). Variable philosophical positions of researchers and their research have culminated in a spectrum of terminology and processes (Seale, 1999; Golafshani, 2003). This is echoed within an interpretivist-constructionist orientation where an array of methods to assess or ensure quality has been reported (Seale, 1999).

This study was an ethical, humanistic, relational inquiry. The notion that 'narratives sit at the intersection of history, biography, and society' (Liamputtong and Ezzy, 2005, p. 132) was held. The context, the teller, and the audience are inextricably linked through an encounter where the story is co-constructed. This identifies that narrative is relational and therefore the researcher brings a value and

takes a position of privilege (Riessman, 2001; Josselson, 2007). Furthermore, the analytical approach and method of re-storying is determined by the researcher's interpretation and representation, based on choices that involve both morality and ethics (Liamputtong and Ezzy, 2005).

Holloway and Freshwater (2007) argue that quality can be compromised if analysts provide interpretation of the data without situating themselves. This involves researchers being transparent and open about their position within the inquiry for interrogation by the reader. Therefore, reflexivity was central in situating the researcher within the study (Davis, 1998; Burr, 2003). An analytical tool for stimulating relational and performative reflexivity was used in addition to the narrative psychological analysis. Two of the situational questions from Riessman's (2001) process of narrative inquiry were used: (1) how does the narrator position himself in relation to the audience?; and (2) how do the audience position themselves in relation to the narrator? These were presented within each case study report to provide the reader with an understanding of how I was situated for each case study and how this evolved during the data collection period.

Furthermore, each stage of the analysis process was subject to interrogation during PhD supervision and the feedback that was received assisted in reflection, development and refinement of the findings.

3.6   Chapter Summary

This chapter has provided a detailed discussion of the ethical, child-centred strategy used in this study. A firm rationale for the use of collective qualitative case studies, with an embedded narrative approach, has been outlined and located within qualitative health research literature. The tool-box of methods utilised to collect survivor stories and those stories of people significant in their lives have been explicated. The sampling strategy has been expounded and the procedures employed to recruit, consent, collect and analyse data, and ensure quality of the research, have been presented.

Chapter Four
Findings: Study participants and case profiles

4.1 Introduction

This chapter presents an overview of the recruitment process, composition and profile of study participants and each case study. The chapter is divided into three main sections:

- The first section outlines selection and recruitment of child and adolescent survivors into the study, who were central to each case study.

- The second section describes the socio-demographic and critical illness characteristics of these participants. Information as to the geographical, social, and diagnostic heterogeneity of the sample is outlined.

- The final section discusses the composition and sources of data collected from each case study.

Throughout this, and subsequent, chapters, identifiable information about persons and locations has been changed to maintain the confidentiality and anonymity of the participants. The main participants in the study (PIC survivors) have been given pseudonyms, for example "Tim", whereas all the other participants or locations have been given descriptive pseudonyms, for example "Tim's Mother".

4.2 Participant recruitment, consent and withdrawal

4.2.1 Participant recruitment and selection

The screening, recruitment and selection of participants was undertaken in the Autumn/Winter 2012. A summary of the screening and recruitment process is presented in Figure 15 (page 95).
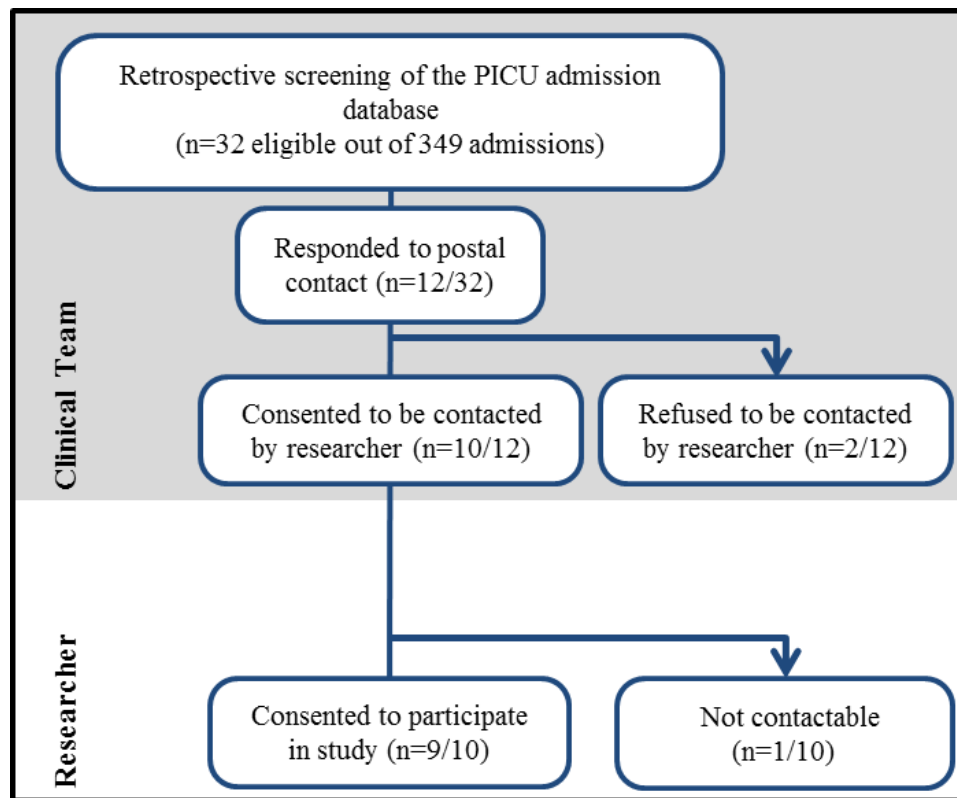
Figure 15: Screening and recruitment flowchart

Eligible child and adolescent PIC survivors were identified through retrospective screening and contacted over a three-month period, from 7th September 2012 until 7th December 2012. Screening identified that a total of 349 infants, children and adolescents had been admitted and cared for in PICU over a nine-month period (capturing the survivor at three to 12 months post-PICU admission), between September 2011 and June 2012. Thirty-two of these patients fulfilled the eligibility criteria.

The status of the eligible children and adolescents was checked on the hospital electronic patient admission system to: (1) ensure they had not died since PICU discharge [n=0/32]; (2) confirm their contact details (postal address and telephone number) were accurate and correlated with the records held on the PICU database [n=3/32]; and (3) check whether they were receiving on-going care from a clinical team [n=7/32]. Permission to proceed to contact survivors in receipt of ongoing care was obtained from all clinicians leading their care.

Due to the small number of eligible survivors it was decided, in consultation with the study steering group, that the theoretical sampling framework should not be

used. Instead all eligible PIC survivors (n=32) were sent a study invitation letter and information sheets (Appendix E) by the clinical team. In total, three responses (n=3/32) were received within the 14-day period. Reminder letters were sent to all non-responders (n=29/32) in an attempt to increase the response rate with 13/32 PIC survivors responding, yielding a response rate of 37.5%. From these 13, two parents explicitly indicated that they did not consent to be contacted. Out of the remaining 11 respondents consenting to be contacted, one was received outside of the recruitment period and therefore could not be included in the study[24]. Ten responses containing designated contact (e.g. parent) and the preferred method of communication (e.g. mobile telephone) were provided by the clinical team.

All designated contacts were parents who requested to be contacted by telephone. All parents confirmed willingness to participate in the study and arranged for an information visit. None of the parents requested that I should be accompanied by anyone in the study team. Questions were raised by the parents which centred on two main themes: whether their child was 'worthy' of participating in the project as they perceived their critical illness being not as severe as other children, or their child as having recovered from the critical illness without residual physical impairment; and whether their child was 'able' to provide useful information for the study. I stressed that the project aimed to explore the experiences of a range of children with varying outcomes and abilities and would welcome their participation.

4.2.2 Study information visit

Study information visits were conducted between 1st October and 3rd December 2012 for all 10 respondents. However, one respondent was not present at the agreed location and time for the visit. Despite attempts to contact the respondent (mobile telephone and landline, voicemail messages left, and letter sent through postal mail), this was to no avail. Inquiries by the clinical team identified no hospitalisation or safeguarding concerns and, therefore, no further contact was made with the respondent.

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24 Respondent not included as this would have resulted in a protocol violation. However, the participant and their parent(s) were sent a letter from the study team acknowledging their response, thanking them, and explaining why they could not be included in the study.

The remaining nine respondents received an information visit conducted in their own home. The majority of visits occurred on a weekday evening, as this appeared the most convenient time to fit around the school day. All nine visits were attended by the child/adolescent and their parent. However, seven of these also included another parent, sibling(s), cousin(s), and/or friend(s) being present. These visits lasted between 45 minutes and 1.5 hours and a schedule was used (Appendix A) to provide structure and a prompt.

4.2.3   Consenting and assenting

As outlined in the study procedure (section 3.5.4, page 77), I requested consent from the child/adolescent and their parent(s) at the end of the information visit. As all eligible participants were aged less than 16 years, in addition to their assent to participate in the study, written consent was also required from an adult with parental responsibility. No conflict between the child/adolescent and their parent was observed in terms of their willingness to participate and written consent was obtained from all (n=9/9). Due to the longitudinal data collection phase of this study, I explicitly asked each child/adolescent to confirm willingness to participate in the study at the beginning of each data collection visit.

4.2.4   Study participation and withdrawal

Eight out of the nine participants remained in the study for the six-month data collection period. In order to ensure that participants felt able to withdraw from the study, a number of options were available in which this could be communicated which included: face-to-face, telephone, email, text message, and postal mail. Only one participant (Case study Seven – Andrew) withdrew from the study after one data collection visit. His intention to withdraw was communicated via an email from his father and the circumstances for withdrawal are outlined in Chapter Five (page 156). The participant was not replaced but data collected prior to his withdrawal were used.

4.3 Participant characteristics

4.3.1 Socio-demographic characteristics

Nine children and adolescents participated in the study and a summary of their socio-demographic data is presented in Table 12. The National Codes for ethnicity were used as defined by the Health and Social Care Information Centre and used in the 2001 census. The ethnicity of the survivor was specified by the participant or on their behalf by their parent. The survivors formed a homogeneous sample in relation to their ethnicity as the majority were white British. However, heterogeneity was evident from the other socio-demographic indicators such as age, household composition, geographical locality, and socio-economic status.

Survivor	Gender	Age	Ethnicity	Household composition	Index of Multiple Deprivation Score (rank)[25]
Tim	Male	7	White British	Mother, Father and Sister	4.84 (30215)
Sarah	Female	8	White British	Mother	54.25 (1516)
James	Male	12	White British	Mother and Brother	8.4 (26102)
Clare	Female	9	White British	Mother, Father and two Sisters	6.39 (28538)
Steve	Male	11	White British	Mother and two Sisters	19.77 (14148)
Katherine	Female	15	Black African	Mother and Brother	68.80 (286)
Andrew	Male	6	White British	Mother, Father and Brother	13.95 (19284)
Mark	Male	12	White British	Mother, Father and Brother	13.66 (19612)
Ollie	Male	7	White British	Mother, Father and Brother	29.28 (8521)

Table 12. Survivor demographics and order recruited into the study

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25 Index of Multiple Deprivation devised from the participants' postal code. http://opendatacommunities.org/deprivation/map [accessed 20th January 2014]. A lower rank, or higher score, means the area is more deprived: 1=most deprived, 32482=least deprived.

Participants included six males and three females whose ages ranged from six to 15 years ($\tilde{x}$ = 9 years) at the time of consenting, with six children/adolescents celebrating a birthday during the data collection period.

All study participants lived in the East Midlands, which is located on the central East side of the England (shown in Figure 16). Despite living in the same region, the sample was geographically disparate, covering six counties.
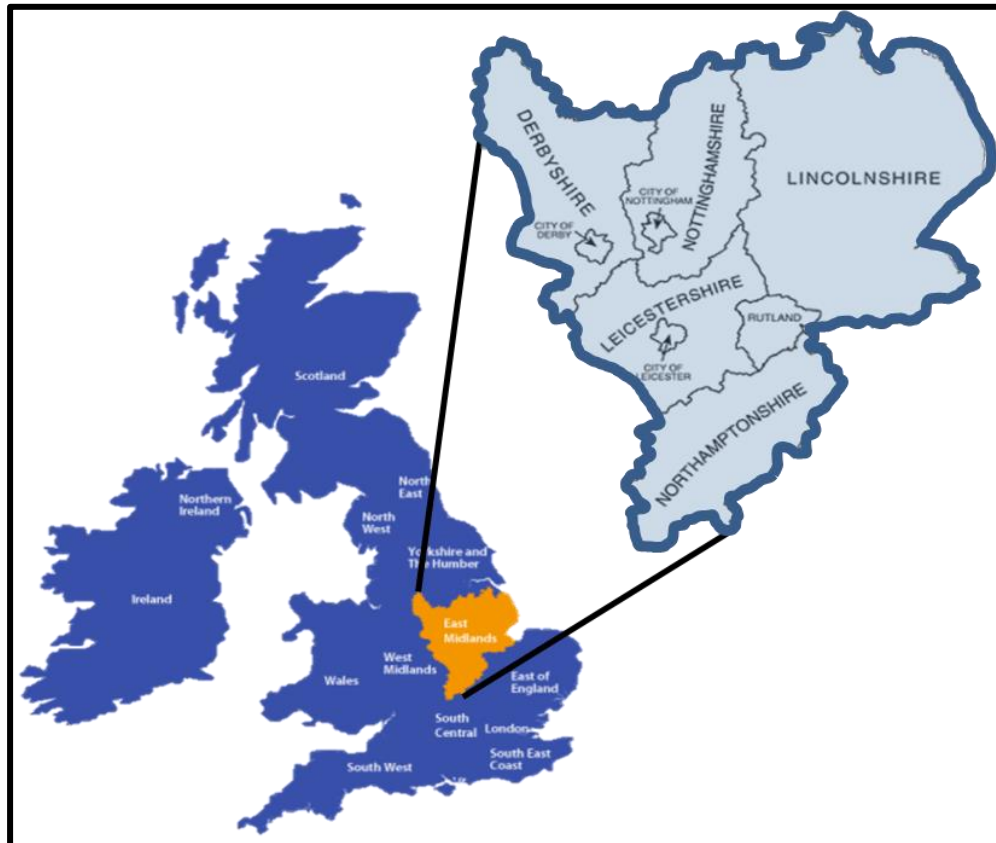
Figure 16: Map of the East Midlands showing the location of study participants and case studies

The socio-economic status of participants was derived from the Index of Multiple Deprivation (McLennan, Barnes, Noble et al., 2011). The index is based on Local Super Output Area (LSOA) [26] data. The majority of participants (n=5/9, 55.5%) lived in the least deprived 50% of LSOAs in England, but two survivors (Sarah and Katherine) resided in the most deprived 10%.

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26 LSOA are geographical areas devised to be of a consistent size generated in a consistent way across the whole of England. The total population of each LSOA total 1500 people.

Household compositions varied across participants with the majority of participants (n=8/9, 88.8%) cohabiting with at least one sibling. Four survivors lived in households with a single parent.

4.3.2 Critical illness and health-related characteristics

Study participants varied in characteristics that related to their critical illness and receipt of ongoing healthcare as shown in Table 13, below. The reason for admission, time since critical illness, underlying condition, and receipt of ongoing care varied amongst the sample.

Survivor	Reason for PICU admission ICD-10[27]	Time since critical illness at consent (months)	Time since critical illness at final data visit (months)	Underlying medical condition	Receipt of ongoing care
Tim	Sepsis	11	17	No	No
Sarah	Respiratory	6	12	No	Yes
James	Neurological	11	17	Yes	Yes
Clare	Trauma/ Neurological	7	13	No	No
Steve	Respiratory	12	18	Yes	Yes
Katherine	Sepsis	13	19	Yes	Yes
Andrew	Neurological	6	-	Yes	Yes
Mark	Respiratory	14	20	Yes	Yes
Ollie	Neurological	11	17	No	Yes

Table 13: Overview of critical illness and health-related characteristics of survivors

Heterogeneity was evident in participants' reasons for admission to PICU with variation in presenting condition as defined by the International Classification of Diseases (ICD)-10[28] (World Health Organisation, 2005), captured by the participants' screening data. At the point of consenting to participate in the study, time since the survivors' critical illness ranged from six to 14 months ($\tilde{x}$ = 11 months). Furthermore, time since critical illness at the final data visit ranged from

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27 ICD-10 (international classification of diseases 10) of disease that resulted in PICU admission as defined by the child/adolescent survivor or their parent.

28 The International Classification of Diseases (ICD) is the standard diagnostic tool for epidemiology, health management and clinical purposes. http://www.who.int/classifications/icd/en/ [accessed 15/09/2013]

12 to 20 months ($\tilde{x}$ = 17 months). The data collection phase, therefore, captured data from participants six to 20 months post-PICU discharge.

Prior to PICU admission the sample varied in relation to receipt of healthcare with 55.5% (n=5/9) of participants accessing healthcare services. However, homogeneity was apparent in the sample in relation to receipt of healthcare post-PICU. Only two participants (22.2%) were not receiving any hospital or community care at the point of consenting into the study.

4.4   Case study composition and data collection

4.4.1   Recruitment and consent of significant others

A total of 32 survivors and significant others participated in the study. The nine critical illness survivors identified 23 significant others who consented to participate. This was achieved through the chain referral method, as outlined in Chapter Three. Significant others most commonly included family members, as shown in Table 14 (page 102).

In total, nine mothers, four fathers, seven siblings, and a grandparent of survivors participated, as well as a teacher and a speech and language therapist. The consenting process for significant others followed the procedure described in Chapter Three. Six out of the seven siblings were under 16 years old and, therefore, required parental written consent in addition to their own assent. In all cases, the parents had previously consented for the survivor to participate in the study and appeared very willing for their other child/children to do so. However, it was made explicitly clear during the consenting process that the sibling was not obliged to take part and could refuse to consent or could withdraw during the data collection visit. The siblings appeared excited to be involved in the study as many had been present during my interaction with the survivor and were, therefore, familiar with the toolbox of methods.

Case study	Survivor	Number of data collection visits	Total audio data (minutes)	Total visual data (images)	Significant others	Number of data collection visits	Audio data (minutes)	Visual data (images)
1	Tim	3	83	27	Mum; Dad; Sister	2	73	2
2	Sarah	3	189	44	Mum; Gran	2	57	-
3	James	4	241	157	Mum; Brother; Teacher; Speech and Language Therapist	3	133	5
4	Clare	3	120	75	Mum; Sister (1); Sister (2)	2	117	4
5	Steve	3	113	30	Mum; Sister (1); Sister(2)	2	76	4
6	Katherine	3	131	25	Mum	1	48	-
7	Andrew	1	53	6	Mum; Dad	1	136	-
8	Mark	3	116	9	Mum; Dad	1	62	-
9	Ollie	3	154	39	Mum; Dad; Brother	2	104	-
Grand total:		**26**	**1200**	**412**	**23 Significant others**	**16**	**806**	**15**

Table 14: Summary of case study composition, data collection visits and sources of data collected

4.4.2 Data collection

Data collection was undertaken between October 2012 and July 2013, with each case study explored over a six-month period[29], shown in Figure 17 (page 104). Child and adolescent survivors differed according to time since PICU discharge and, therefore, across survivors the data collection phase covered six to 20 months post critical illness.

Interviews were conducted in person, at a convenient date, time and location for the participants. All visits were conducted in the participants' homes apart from two which were conducted in a local café at the participant's request (Sarah, DCV3; James' Brother DCV). In between interviews, survivors were able to construct their stories through the collection of photographs, drawings and personal written reflections.

Each significant other identified by the survivor received one interview during the data collection period. For all case studies where both parents (mother and father) participated as well as the case study with the teacher and speech and language therapist, the interviews were conducted together, at their request.

At the end of each visit, the participant was asked whether they wanted to receive a transcribed version of the interview. Apart from Andrew who withdrew from the study, all participants requested a copy of the transcript via postal mail. Accompanying this transcript were covering letters inviting the participant to make any changes to the script. However, no requests for changes were received from the participants.

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29 Apart from case study seven (Andrew) who withdrew consent after the first visit.

Case study		Data collection 2012				2013						
		Sept	Oct	Nov	Dec	Jan	Feb	March	Apr	May	June	July
1	Tim		C	D, S1,2		S3	D		D			
2	Sarah		C, D		S1	D		S2	D			
3	James		C, D	D	S1	S2	D			DS3		
4	Clare		C, D		S1	D		S2,3	D			
5	Steve			C, D			D, S1			D, S2,3		
6	Katherine			C	D			D	S1		D	
7	Andrew			C	D	W, S1,2						
8	Mark			C		D			D		S1,2	D
9	Ollie				C	D	S1,2		D			D, S3

Table key: C=information visit and consent; W= withdrew consent; D= data collection visits; S= significant other data collection visits

Figure 17: Overview of case study data collection period

4.4.3 Data sources and analysis

Data were collected in two main forms: images from participant drawings and photographs; and audio data from the interviews. As outlined in Table 14, the child and adolescent survivors created a total of 1200 minutes of audio data and 412 images over 26 data collection visits. Moreover, significant others produced 806 minutes of audio data and 15 images over 16 data collection visits.

Data were informally analysed to gain insights into the emerging narrative imagery and themes during the data collection phase in order to inform topics discussed at the next visit. This was achieved by conducting all the interviews myself, listening and transcribing the audio data and inserting the visual data into the transcripts at the point of reference.

Formal data analysis was conducted from March 2013 to June 2014. This involved prolonged engagement with the data from each case study and resulted in a comprehensive report being written for each case study. Each report included the individual narrative analysis of the stories from each participant and within-case analysis. Reports ranged from 28,000-66,000 words and included a case summary, individual narrative analysis of each participant, tables of imagery, themes and the data excerpts/images to support these, within-case analysis and themes. To assist with reflexivity and to expose the analysis to interrogation from others with different analytical lenses, each case study report was read and commented on by both PhD supervisors. These comments were discussed at length during researcher supervision meetings, providing a platform for the analysis presented in the subsequent three chapters.

4.5 Chapter summary

This chapter has detailed the process for enrolling critical illness survivors into this study, reflecting on some of the practical and ethical challenges faced. The numbers of participants that were recruited into the study have been reported. The variation in relation to socio-demographic and critical illness characteristics has been detailed demonstrating the overall heterogeneity of the sample.

Furthermore, information pertaining to the case study composition and the period of involvement, type and sources of data collection has been expounded. Collectively the information presented in this chapter contributes to contextualizing the qualitative data findings that will be presented in the following three chapters.

Chapter Five

Findings: Childhood survivors of critical illness and their re-storied narratives

5.1   Introduction
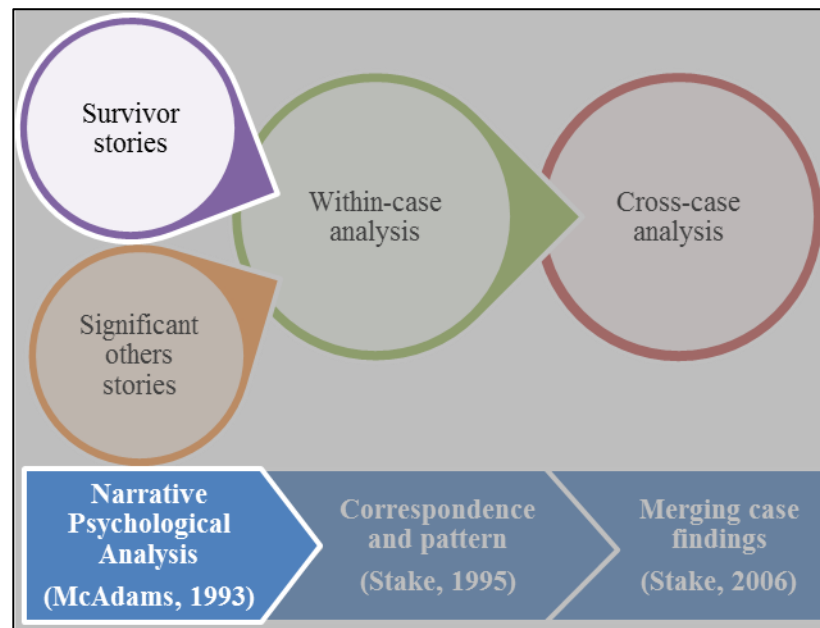
This chapter presents a vignette of each PIC survivor and their re-storied narrative to provide a rich understanding of the individuals central to each case study.

Vignettes have diverse application in qualitative research (Barter and Renold, 1999) as a data collection method, such as an ice-breaker during interviews, or as a data source during dissemination to allow findings to be presented in context (Hughes and Huby, 2002, 2004; Crafter, De Abreu, Cline et al., 2010; Jenkins, Bloor, Fischer et al., 2010). Vignettes are used within this chapter to provide context of the PIC survivors' lives and were developed from contextual audio and visual data that were collected during the data collection phase, as well as the notes[30] documented during the study period.

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30 Notes included informal and unstructured observations, personal experiences and reflections documented during the data collection and analytical stages of the study. These were captured on

The process of "re-storying" a story from original raw data involves: co-constructing the data, transcribing, reading the transcript, analysing the story to understand the lived experiences, and then retelling the story (Clandinin and Connelly, 2000; Ollerenshaw and Creswell, 2002). Each survivor's narrative will then be retold through a summary of their 'life story' (Crossley, 2000; McAdams, 2008). Insights into survivors' psychological and social worlds will be gained through the metaphors, imagery and descriptions within their stories.

Providing reflections for public scrutiny is considered a key element of ethical and rigorous qualitative research (Bishop and Shepherd, 2011). Researcher reflexivity will therefore be expounded throughout this chapter to critically situate the narrator (PIC survivor) and researcher. In addition to reflexivity, data excerpts from the visual information and interview transcripts will also be presented to provide transparency and a platform to position the findings from qualitative data analysis presented in subsequent chapters.

5.2   Tim
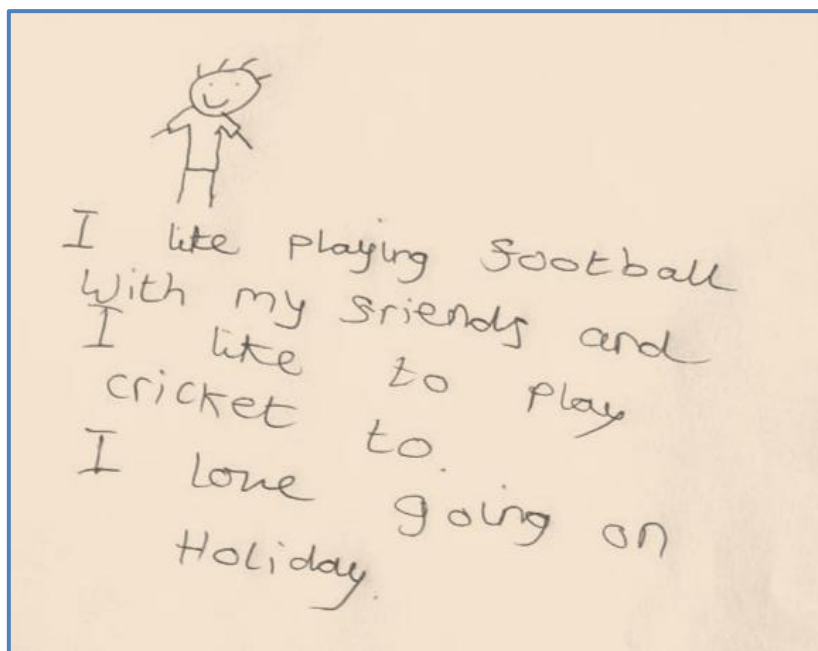
Image 3: Self-portrait (Tim, DCV3)

Tim is an eight year old boy who attends a local primary school full time (Year 3). He lives in a detached house in a village on the outskirts of a large city with his

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the page in a reflective journal or through audio dictation when writing was impossible (e.g. whilst driving back from a data collection visit).

mother, father and older sister. Tim was seven when he commenced the study and had experienced an acute life-threatening event 11 months prior to this. Tim had become critically ill through developing a neck swelling and sepsis. He was on PICU for two days and was sedated and invasively ventilated. Tim received three data collection visits, after school on a weekday, with his sister and both parents present.

5.2.1 Tim's story

Tim's story is one of positivity, fun and happiness. Despite including some negative events of physical and emotional trauma, his story focuses on a life that is unchanged and predominantly unaffected. Tim constructs a story within a somewhat bounded narrative repertoire[31] which re-occurs through his telling and re-telling. An example of this is from Tim's time-lining activity (Image 4) where he draws and discusses generic activities as opposed to events that have occurred at specific time points.

In Tim's story it appears that, from a 'normal' life filled with fun and activities, his critical illness exposes him to negativity in terms of unpleasant physical symptoms such as nausea, separation from his family, restriction and disablement. However, Tim later reports being redeemed from this negativity and that his life is filled with positive imagery, fun and happiness where he is able to achieve his ambitions. Collectively Tim's story appears to align to a redemptive sequence as it involves a linear story which begins and ends with positive imagery but contains negative or 'bad things' in between (McAdams, 2006, p.20).

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31 Meaning that recurrent themes manifest through the three interviews e.g. football, playing football, playing with sibling/friends, going on holiday.
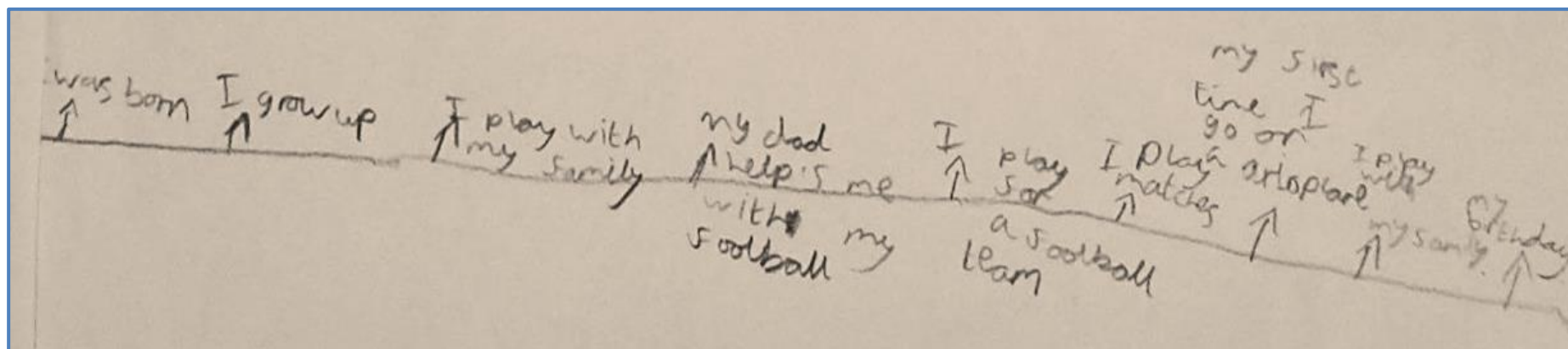
Image 4: Timeline (Tim, DCV2)

Chapter one

Tim's first life chapter relates to becoming ill and the medical investigations to which he was exposed. This emanates predominantly from his first interview where he reports the physical discomfort experienced when he became unwell. Tim appears not to ascribe direction to the imagery used in this chapter as he recalls events as largely unknown.

> 'Tim: *I was in hospital because I had a sore throat and I kept on burning up....*
>
> ....Joseph: *Okay. So you were feeling poorly. Okay. Can you remember anything else after you were there?*
>
> Tim: *no...*
>
> ...Joseph: *...So when you came out of intensive care where did you go?*
>
> Tim: *ummm*
>
> Joseph: *It doesn't matter if you can't remember.*
>
> Tim: *ward.*
>
> Joseph: *You did go to the ward?*
>
> Tim: *yeah'*
>
> *(Tim, DCV1)*

Tim clearly describes his experience of having an MRI scan and the effect of being injected with radiographic contrast, ascribing negative imagery, not to the process of being scanned but to the aftermath and feeling sick.

> *'Joseph:*   *Where is that?*
>
> *Tim:*   *uh that was when I was in hospital there's the TV the TV there's in front of me and then I went to this um this little um round tube um and then this the scan me or something and then I came out and I felt sick.*
>
> *Joseph:*   *Oh dear*
>
> *Tim:*   *because they had put something in me'*
>
>   *(Tim, DCV1)*

Chapter two

This chapter involves hospitalisation and Tim's journeys of health status and geographical location. He provides imagery of the hospital environment, describing vividly the equipment in, on and near him. He does not affiliate any reactions, thoughts, feelings or emotions to these descriptions and his critical illness experience itself is forgotten. Negative imagery of Tim missing out festive activities and being with his family is described. However, whilst on-leave from hospital, Tim reports conflict with his parents. This arises from his determination for independence being undermined by the physical assistance that others imposed upon him.

Within this life chapter, Tim's discharge from hospital appears pivotal to confirmation that he was recovered. The doctors were identified as fundamental to his recovery, as they verified he was better. Tim acknowledges the responses of others (parents) around him to the news with positive imagery which infers the inter-dependency and relatedness of Tim's emotional status to that of his family members within his story.
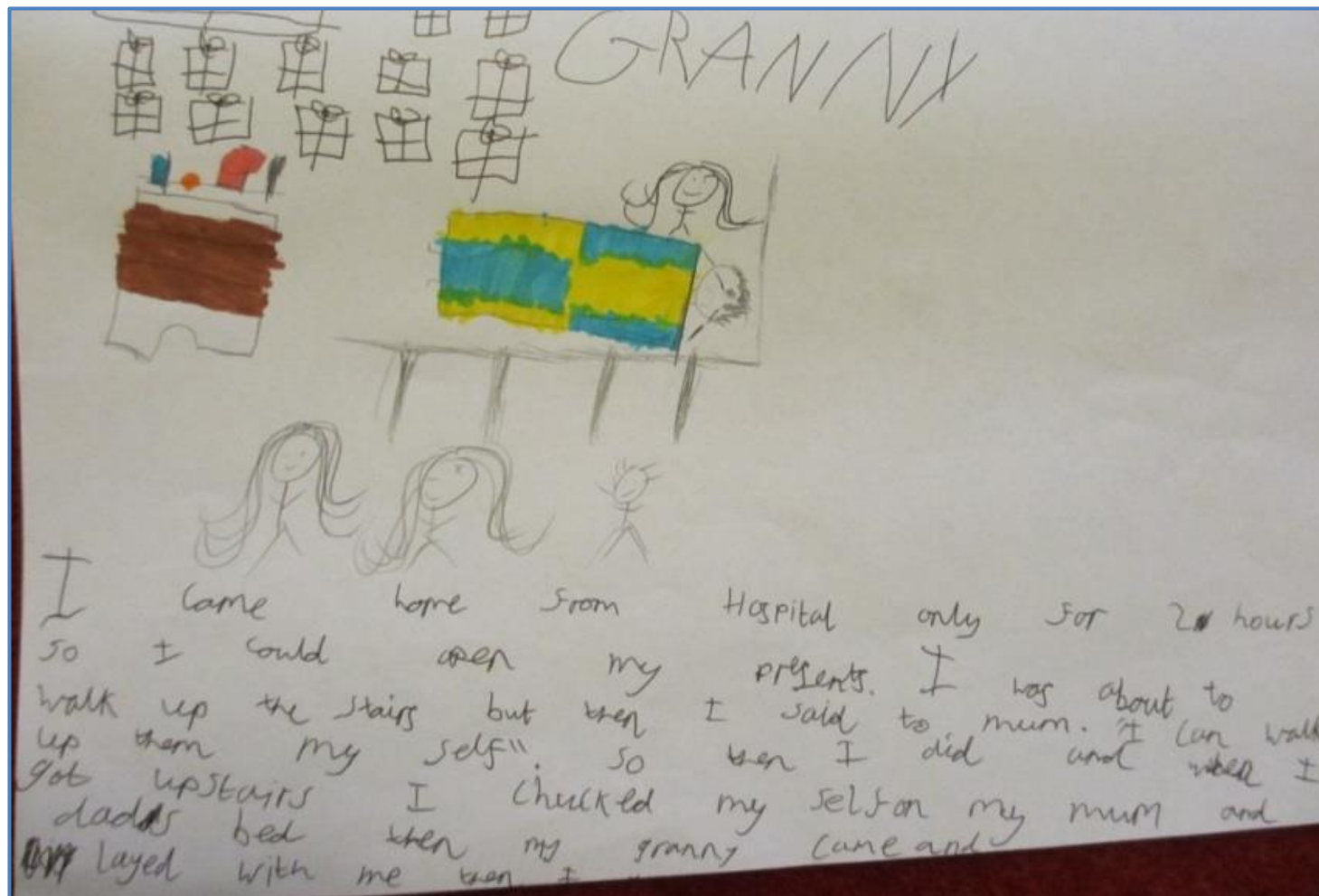
Image 5: Tim, DCV1

I came home from Hospital only for 2 hours so I could open my presents. I was about to walk up the stairs but then I said to mum. "I can walk up them my self". So then I did and when I got upstairs I chucked my self on my mum and dads bed then my granny came and played with me then I

Image 6: Tim, DCV1

Chapter three

The final and most dominant chapter of Tim's story involves his life now. Tim constructs himself as an individual defined by the activities he undertakes and his interests which are largely unchanged across the three interviews. He relays positively his enjoyment in undertaking sport and football, only referring fleetingly to the impact and restriction that minor illness and his hospitalisation had in inhibiting him from engaging with it. The focus on football does not appear to change across the interviews and the prominence that Tim places does not wane, which is confirmed through his aspirations to become a professional footballer and have the lifestyle that accompanies such.
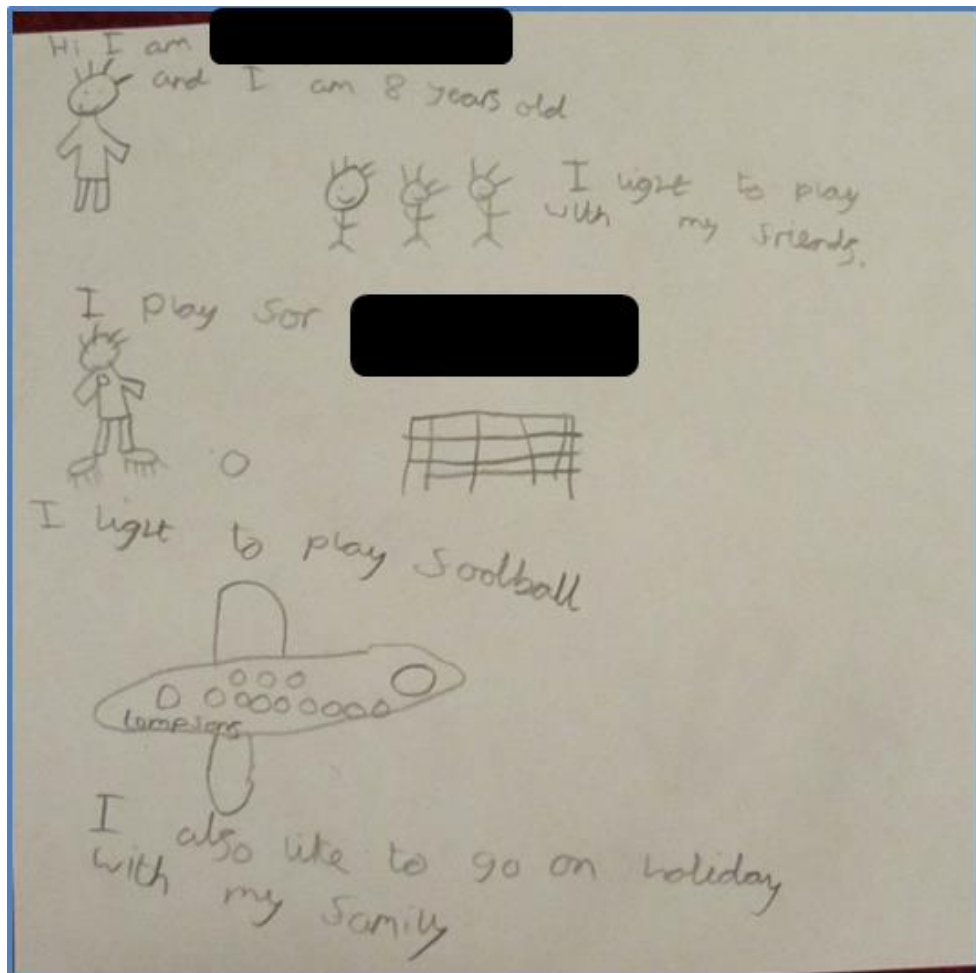
Image 7: Tim, DCV2
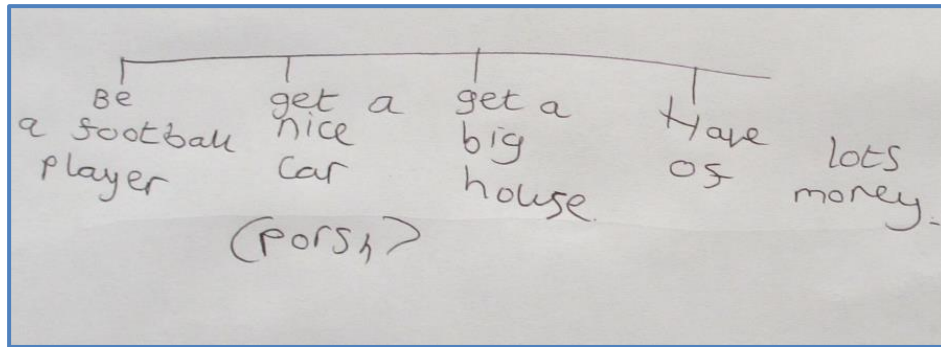
Image 8: Tim, DCV3

However, Tim uses football not just as an activity but also as a currency for social engagement. Football appears to enable and strengthen the paternal bond that Tim has with his father, as well as providing a social platform to engage with his peers.

> '*Tim:*   *Well when I grow up I want to be a professional football player. And my dad says I play really good at football. At school I like to do big writing, and I play with my friends at playtime, I play games and football with them. And I play for [football team name], I play matches for them and I train with them…*   *(Tim, DCV3)*

Tim identifies the significance of his family and friends for the provision of support, guidance and to play with. They are constructed as enablers in defining his self and social identities. His story oscillates between decisiveness about what he wants to achieve in life and the need for permission and reassurance from his parents to realise his ambitions.

> '*Joseph:*   *So can you tell me what sort of person they are that you've drawn there?*
>
> *Tim:*   *I don't know.*
>
> *Joseph:*   *Is it a happy or a sad person?*
>
> *Tim:*   *Happy.*
>
> *Joseph:*   *Okay, and why is it happy?*
>
> *Tim:*   *Because it has a lot of friends.*
>
> *Joseph:*   *Okay, and why do the friends make that person happy?*
>
> *Tim:*   *So then I'm not lonely and I have someone to play with'*
>
> *(Tim, DCV3)*

5.2.2   Researcher reflexivity

At the initial information visit Tim appeared slightly reserved and shy. However, from the first interview he was eager and comfortable to tell his story. Tim was one of the first participants in the study and, therefore, during the initial interviews I was relatively inexperienced. This could have influenced how Tim positioned

himself in his story. My inexperience with the phrases Tim used could have resulted in a lack of understanding, thus provoking the default answer -'I don't know'. Secondly, I was fearful of inciting a negative response from Tim, or his parents, which may have inhibited me from probing certain responses and thus limiting clarification and understanding of certain aspects of Tim's story. However, through recurrent engagement with Tim during the study period, I became more confident and able to explore issues and concepts with him. During the interviews Tim's parents and sister did interject. It appeared that this was to provide support to Tim in telling his story, for example to clarify a word he had written down or a point Tim or I attempted to make.

5.3   Sarah

Image 9: Self-portrait (Sarah, DCV1)

Sarah was born and has spent her childhood in a town on the east side of the East Midlands. She lives in a first floor flat with her mother. Her parents are separated and she has not had any contact with her father for the past three years. Sarah is an only child and attends a local Primary school full time (year three). On commencing the study Sarah was eight years old. Six months prior to her first data collection visit Sarah became critically ill after experiencing a life-threatening asthmatic episode. This was her first episode of asthma and she was previously fit and well. She was on intensive care for three days and was sedated and invasively ventilated. During Sarah's involvement in the study she was still receiving treatment (medications) and regular check-ups for her asthma.

5.3.1 Sarah's story

Sarah's story is dichotomous with a mixture of positive and negative imagery and tones. She constructs a story of epiphany and quest. Epiphany emanates from her critical illness hospitalisation that coincided with her asthma diagnosis. She constructs this as a point in her life where negative emotions and worries began to manifest. Sarah poses a subsequent quest to navigate between her undulating health status, and her desired prior self.

Chapter one

Sarah's first chapter focuses on life before asthma. Imagery of freedom and fun is posed and alludes to her positive and healthy personal, emotional and social identities. However, she also uses imagery as a platform for comparison to the different self- and social-identities that she has become. This chapter is tarnished by some negative imagery in relation to events, such as the death of her dog, and significant others, such as the separation of her parents. These events are associated with imagery of trauma, grief and personal reflection.

> *'Sarah:*   *We haven't got to take a picture of my other dog, because he died ages ago when I was four. It was very sad because I wasn't actually, because we lived at my grandma's house at that point, but then we went to move at my mummy's friend's house. Then we just got a very sad phone call one day, and it just shocked me, it made me feel really upset.'*
>   *(Sarah, DCV2)*

Sarah appears to cope through her story by internalising the blame for this lack of contact with her father by ascribing his dislike of her as the reason.

> *'Sarah:*   *One that I don't like is my dad*
>
> *Joseph:*   *Okay…and why is that?*
>
> *Sarah:*   *Because. I don't think he likes me. Because when I was little he went away. And he lies to me all the time.*
>
> *Joseph:*   *Okay*
>
> *Sarah:*   *And I don't like him…it's really sad I don't like it*
>
> *Joseph:*   *Okay does that upset you?*
>
> *Sarah:*   *A little bit when I think about it upsets me a little bit'*
>   *(Sarah, DCV1)*

Chapter two

Chapter two involves imagery of Sarah's physical deterioration, critical illness and subsequent rehabilitation. It begins with descriptions of her physical deterioration

and her panic and fear that emanate from her physical symptoms as well as the uncertainty surrounding the event. From this confusion, she constructs movement through multiple transitions in relation to care and her own physical health, reflecting her undulating and vulnerable health status.

> 'Sarah: ...because when I just before I actually went to the hospital I can remember not being able to breathe properly and went outside to get some air with my grandma and then I was starting I can't breathe really panting and grandma said shut up people will think there's something wrong with you and I said something is wrong with me I can't breathe'   (Sarah, DCV1)

Her intensive care admission is an event that is largely forgotten, described as 'being asleep'. Although Sarah's mother's narrative is used within Sarah's story for clarification, it also appears she exposes Sarah to additional adversity. Sarah associates fear and anxieties with being exposed to the critical care experience through the eyes of her mother, whether that be in spoken or visual forms.
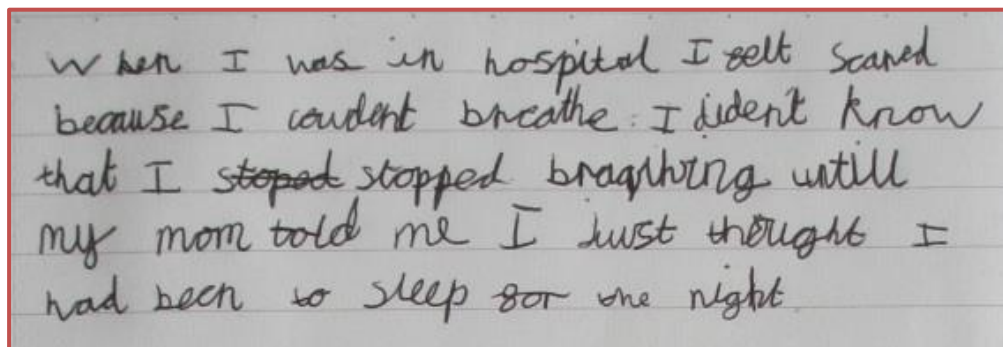
Image 10: Sarah, DCV2

> 'Sarah: And I felt scared because....mummy was telling me what it had been like in hospital and I didn't really like it. I felt scared.
>
> Joseph: Okay. What sorts of things made you feel scared then?
>
> Sarah: Like when she showed me the pictures
>
> Joseph: Okay
>
> Sarah: Of when I had been into intensive care.
>
> Joseph: What sorts of things? Was it just seeing the whole picture there?
>
> Sarah: Yeah
>
> Joseph: Of you in intensive?
>
> Sarah: Both of the pictures made me feel strange
>
> Joseph: Strange? What was on those pictures? Could you describe those pictures for me?
>
> Sarah: Blue
>
> Joseph: Blue. Okay

> *Sarah:*   *The room looked blue and the bed was high and I felt……strange*
> *(Sarah, DCV2)*

Sarah's critical illness is not an isolated event within her story as she alludes to other traumatic events that negatively affect her psychological well-being. She interweaves the sickness and death of her grandad, identifying the loss and grief she experienced, and continues to experience.

> *'Sarah:*   *Just making a thing like that makes me feel sad*
>
> *Sarah's mother: Explain why it makes you feel sad*
>
> *Sarah:*   *Thinking about granddad makes me feel sad because he died*
>
> *Joseph:*   *And when was that?*
>
> *Sarah:*   *Ummm six months ago*
>
> *Sarah's mother: He died a couple of weeks after you got out of hospital didn't he*
>
> *Sarah:*   *Yeah it was a hard time for me then'*   *(Sarah, DCV1)*

Chapter three

The final chapter involves Sarah's life now, living with a chronic condition. Positive imagery dominates the foreground of this chapter with descriptions of professed normality and getting on with life. However, contemplation of her own and others' mortality and thoughts of death feature. Recollections of dreams as well as media images provoke fears, anxieties and negative emotions. Fears are associated with normal life activities, such as being injured playing sports as well as reflecting on her critical illness and vulnerable health status.

Joseph:	*Right, so that's the picture that you drew about how you felt?*
Sarah:	*Yes, because I just remembered how scared I was, and then I felt, I started to write it....*
...Joseph:	*And what sort of things were you thinking about?*
Sarah:	*I kept thinking that, about if it happened again, so I was quite upset then, and in my dream I actually did see one of them.*
Sarah's mother:	*Did you?...*
...Sarah:	*Yeah, I saw one of them in my dream.*
Joseph:	*One of the worry holes?*
Sarah:	*Big black worry hole.*
Joseph:	*And how does that make you feel?*
Sarah:	*It made me feel really rubbish.*
Joseph:	*Worried?*
Sarah:	*Yeah.*
Joseph:	*And what sort of things were you worrying about?*
Sarah:	*I was worrying about if it would happen again, or if it would stop me from breathing and I'd have to get incubated again.'*

<div align="right">

(Sarah, DCV2)

</div>

> I had a dream and grandma gave me her heart.
>
> I was scared a ball might hit my face in rounders
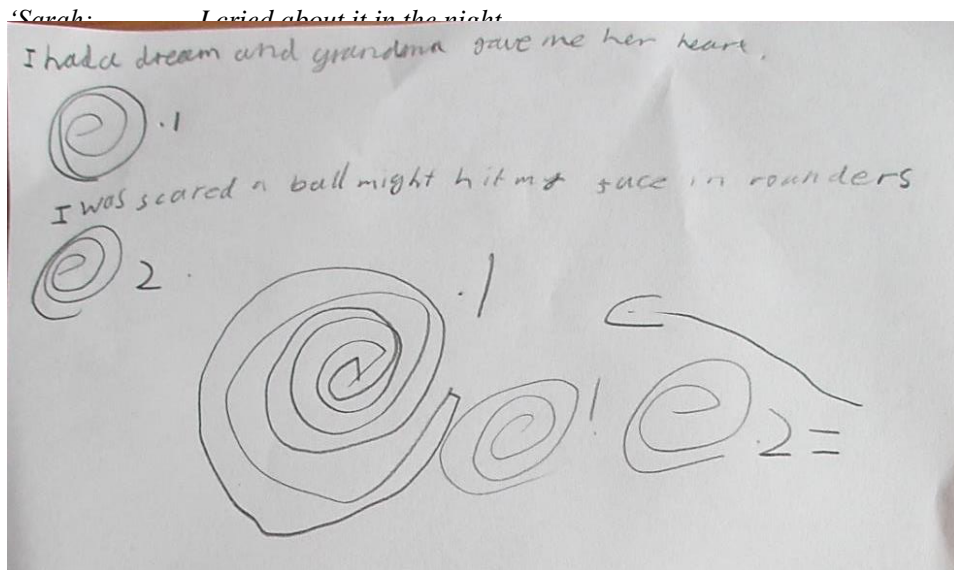
Joseph:	The other night?
Sarah:	Because she died.
Joseph:	And why did grandma give you her heart?
Sarah:	Because I was poorly.
Joseph:	And what were you poorly with?
Sarah:	My heart didn't work properly.
Joseph:	Okay.
Sarah:	And grandma gave me her heart, best thing that ever happened to me…. *(Sarah, DCV3)*

Sarah alludes to the mechanisms that she utilises in an attempt to cope with these negative fears and anxieties. Conscious avoidance of her critical illness is used in an attempt to protect her from the fears that manifest. Within this chapter Sarah constructs a dual and potentially conflicting identity. Her story suggests a disempowered social self, defined by her asthma diagnosis and subsequent healthcare needs, and stigmatized by her peers for being different. It also conveys a resilient and determined self, constructed to overcome adverse emotions, to achieve her own ambitions.

5.3.2 Researcher reflexivity

Sarah demonstrated an openness and rapport with me from the outset. She appeared eager to tell her story, evident from her fluency in disclosing certain aspects of her narrative. Sarah was enthusiastic throughout the study and was particularly interested in the interactive activities such as printing out the photos. She also developed her story outside the visits through writing and drawings.

Sarah used all the tools in the tool-box of methods and was the only participant in the study to use play (and tell). For some of the visit Sarah chose to use her comfort blanket called 'cuddlie' as an adjunct for elicitation, by narrating her story through it.

I approached Sarah's interviews with great interest and experienced polarised feelings of happiness and sadness during our discussions. Sarah was the first child I had visited for the study. I was, therefore, apprehensive from the outset of the visit. However, my anxieties diminished as Sarah was very keen and willing to engage and we developed a good rapport. Sarah's mother was present during the interviews and she did actively participate through her presence as well as dialogue, which acted in a supportive but stimulating role.

5.4   James

Image 11: James, DCV1

On commencing the study James was 12 years old and had experienced an acute life-threatening event 11 months prior to participating in the study. He lives in a detached house on a private estate in a market town in the north-east of the East Midlands with his mother and older brother. His parents are separated and his father co-habits with his partner at a locality close to where James lives.

James has complex health, social and educational circumstances. He was adopted from his birth parents during infancy due to concerns of neglect. His older brother has the same birth parents, and was adopted prior to James, due to physical abuse and neglect. Both James and his older sibling continue to have postal contact with their birth mother. James is reported to have residual attachment issues and a diagnosis of attention deficit hyperactivity disorder (ADHD).

James became critically ill after experiencing a haemorrhagic stroke. He required neurosurgery and PIC for a total of five days, where he was sedated and invasively ventilated. Following his transfer from PICU James received two days' care on the high dependency unit. He had a further seven weeks of care on the ward for rehabilitation for his residual right-sided hemiparesis, memory recall problems, dysarthria (difficulty speaking caused by problems with the muscles used in speech), and verbal apraxia (a speech disorder in which a person has trouble saying what he or she wants to say correctly and consistently). Prior to, and since, his PICU admission, James has regular contact from a range of people and professionals from health, social care and the voluntary sector. He remains under the care of the neurosurgeons as he has had a craniectomy, where the skull flap has not been replaced.

James attends full time education. Prior to commencing the study and his accident James attended a mainstream primary school. However, between the first and second data collection visits he started at a specialist school for children with severe or complex communication difficulties. He receives specialist support for his speech and language difficulties.

James had a total of four data collection visits during the study, with the first interview being conducted over two visits due to James' challenging behaviour. As requested by James, the visits were conducted in his home on a weekday or evening. Both his mother and his older brother were present during the data collection.

5.4.1   James' story

James situates himself in a complex and chaotic experience conveyed through the content and form of his story that does not align to a single narrative genre. A

multiplicity of genres are evident that identify dissociated, redemptive, transformatory and constrained narratives. The majority of James' story is situated in the present. However, his descriptions allude to events and problems from his past that collectively form constrained, muted, traumatic and nostalgic tones.

Chapter one

The first chapter involves James' life before he was critically ill, focused on positive imagery of activities and fun. Although some of these descriptions are distinct and focused on the past, the majority are constructed in his present life, which could be attributed to James' memory recall problems inhibiting him from articulating stories from his past.

James constructs a story featuring an able and independent self and social identity, physically unrestrained and able to exercise his agency. James defines this prior identity as his 'normal' self'.

'James' Mother:	*At his old school before…well he took ill in December he was going to be the sound engineer at school for the school play so he was doing all the lights and the sounds with help.*
Joseph:	*Wow*
James' Mother:	*But then he took ill and didn't do it*
James:	*I am probably if I am probably….*
James' Mother:	*Gonna help with sound at the school play*
Joseph:	*What do you like about doing the sound stuff?*
James:	*It because…I don't know I just like doing it'*

(James, DCV1)
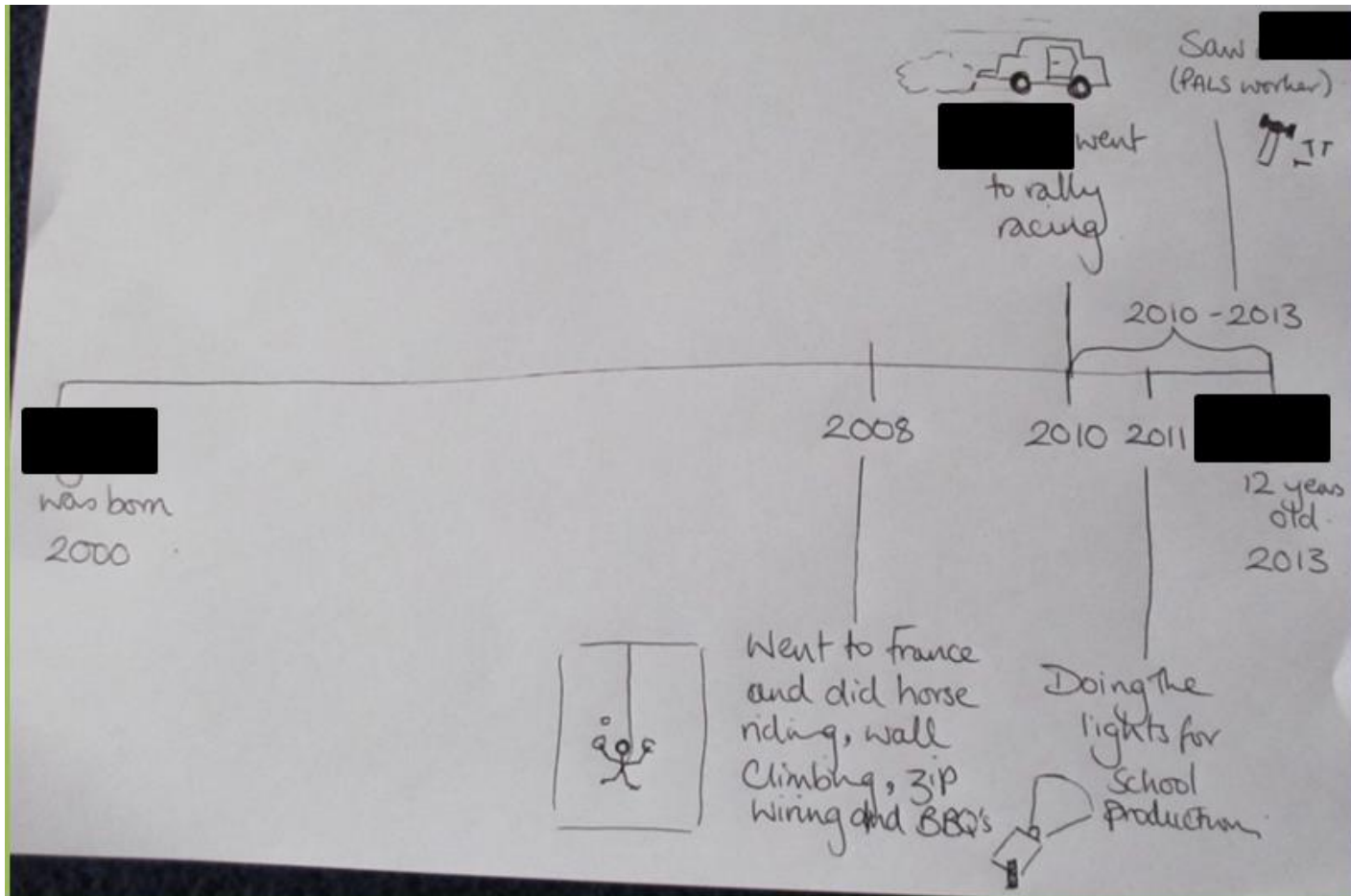
Image 12: Timeline (James, DCV3)

Chapter two

James' second chapter involves 'hospital, ward and home' where diverse imagery of disengagement, unknowns, humour and pain is reported. He constructs his critical illness event as a vacant or avoided part of his story, with exposure through others' accounts provoking aggressive or violent response.

'Joseph:	can you talk me through this photo here? [Referring of photo of child in intensive care]
James:	no!
Joseph:	you can't... Who is this person?
James:	Me.
Joseph:	Where were you?
James' mother:	[siblings name] you can sit down here if you are quiet and let him speak though….don't mess
James:	Something
Joseph:	Something?
James:	Me and I'm doing something that I'm not [sure
James' sibling:	Sleeping
James:	Yes
Joseph:	And this was when you were very poorly. Wasn't it? And you're in intensive care?
James:	That one [pointing to page in Argos catalogue where nerf gun is]'

..James' mother:	can you remember in hospital James when umm shall I tell Joseph what you used to do at a night time
James:	What?
James' mother:	I had to sleep on a camp bed next to James and he had his splints on why did you have your splints on
James:	shut up
James' mother:	and first of all
James:	stop
James' mother:	no I'm telling him what you did. You'd see a splint up [above the cotside
James:	stop…nooo
James' mother:	then a head…then a hand...then he'd take the splints off alright alright calm down I won't then in the morning it was like ET to wake me up for attention wasn't it
James:	stop!'

(James, DCV1 pt.2)

In contrast, James openly reports positive and negative imagery detailing his rehabilitation following critical illness on the ward. Fun, humour and kinship are evident from descriptions particularly from his interactions with health professionals, family, friends and other inpatients. However, negative imagery does manifest, associated with painful procedures encountered whilst an inpatient, with James attributing fears, sadness and hate to the person inflicting the pain.

'Joseph:	Was this it in the photo that NG tube look here [showing photo to child]
James sibling:	Boom
James:	No
Joseph:	That tube up your nose
James' mother:	Yeah
James:	Yeah
Joseph:	So you used to pull that out did you
James:	Yeah
Joseph:	Even when you were sleeping
James:	It hurt
Joseph:	It hurt you did it
James:	Yeah'

(James, DCV1 pt.2)

His story alludes to his prolonged hospitalisation and re-focuses the narrative onto positive imagery of activities undertaken in the hospital school which appears to be an escape from the dominance of healthcare interventions.

Chapter three

The final chapter is the most dominant and involves James' life now. Transitions, transformations and aspirations feature in James' story alluding to the interweaving of an evolving adolescent identity that is navigating newly-imposed physical, psychological and social change. However, the trajectories are not linear and James does not report a redeemed state in any aspect of his self or social identities.

Aspirations of redemption are confirmed by James' fixation on his former able self which appears to provide him with a drive and resilience to achieve. This also poses conflicts as James' aspirations appear not to conform to his abilities, desires and allowances (as enforced by adults). This appears exacerbated by James' lack

of recognition that his disability is restricting and instead ascribes blame to external factors for his difficulties. Collectively, this results in negative imagery of frustration, constraint, anger and destruction.

'Joseph: Is that you up there?

James:	*Yeah...*
..James' mother:	*He felt a bit unsure and coming down he got a bit stuck and panicked a bit. I went just stop, so he went back up again, he thought about how he could do it but he was a bit frightened.*
James:	*No.*
James' mother:	*Oh sorry.*
James:	*No I wasn't, I just couldn't get up because when I get up it's really little.*
James' mother:	*Yeah, but when you were coming down you said you couldn't get down. So what you did you thought about how to do it, you went back up a bit.*
James:	*I know, I was saying that because it was little and I got up then I couldn't get.'*

(James, DCV3)

James constructs an evolving educational and social identity. His residual complex neurological and communication needs impose a transition from a mainstream to a specialist school. James is resistant to this change and reports negative imagery in relation to aspects of moving to a new school, such as the transportation arrangement. He also identifies a disregard for his educational peers and their lack of ability to interact with him. However, this plot changes over the story as positive imagery is related with his transformed educational identity and stronger relationships with his peers. James identifies an evolving self that is

developing a greater skillset and kinship with peers. However, he relies on adults, particularly his mother and sibling, to enable him to do this.
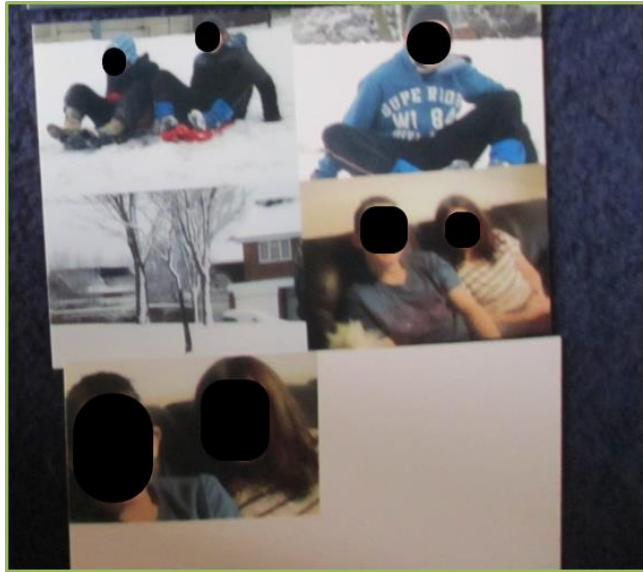
Joseph:	*And is she one of your friends?*
James:	*Mm*
Joseph:	*At school?*
James:	*Mm*
Joseph:	*Excellent.*
James' mother:	*Is she a special friend?*
James:	*Mm*
Joseph:	*What do you like about [school friend's name]?*
James:	*She's funny*
Joseph:	*Funny?*
James:	*Yeah*
Joseph:	*What makes her funny?*
James:	*I don't know….*
….Joseph:	*Did you do anything else whilst she was round?*
James' mother:	*You played games didn't you. And*
James:	*And she didn't want to go home'*

(James, DCV2)

Despite James developing his education identity, he reports a desire for continued engagement and interaction with individuals from his former social and educational worlds. This is accompanied by imagery of frustration and restriction. It is evident from his descriptions that James' interaction is constrained by his

cognitive and communication impairments not allowing him meaningful engagement with others, irrespective of the medium.

> *'Joseph:*   *..Do you want to go back on your computer?*
>
> *James:*   *Yeah*
>
> *James' mother:* *Go on then. I bet I know what you are going on.*
>
> *James:*   *What?*
>
> *James' mother:* *Facebook..yeah..You want to see what's happening with your old friends don't you.*
>
> *Joseph:*   *Have you got lots of friends on Facebook?*
>
> *James:*   *Yeah*
>
> *Joseph:*   *And are they friends from your old school?*
>
> *James:*   *Mm*
>
> *James' mother:* *James finds it frustrating though, don't you James, because all can James really say is 'Hi'. He knows what he wants to say in his head but he then can't process it into the words and you find that frustrating don't you, James.*
>
> *James:*   *Mm'*
>
> <div align="right">*(James, DCV2)*</div>

5.4.2   Researcher reflexivity

James initially displayed a reluctance to engage in a verbal dialogue and instead focused on constructing his story through visual methods. During the study a rapport and openness developed between James and myself, and he appeared more confident and willing to narrate his story. However, this could also be attributed to his residual health and cognitive impairment improving over the study period.

Despite having communication impairments, James effectively used his audience as adjuncts to disclosure. Superficially it could be perceived that James' story is dictated by his audience and in some parts this appears to be the case. However, James does exercise his own agency over his audience to determine what content is included to form his story. This is particularly evident in his dialogue with his mother where James uses her as a 'term finder', demonstrating his understanding and recognition of what he wants to say but inability to recall the term he wants to use. James also used me as a platform for communicating his ideas and experiences. This is particularly evident in activities where James' physical impairment (e.g. limb weakness) could have impeded his full involvement. Like

his mother and sibling, James used me as an adjunct, enforcing his own agency over the creation of his story content.

A number of practical, ethical and methodological challenges manifested during James' involvement in the study that influenced how the audience (such as myself, his mother and brother) positioned themselves in relation to James.

James had pre-existing speech and language problems, limb weakness, as well as a conduct disorder that impacted on how the tool-box of methods was applied. It was evident from the discussion with James' mother during the initial information visit that she had concerns that James would not be eligible to participate in the study due to his communication impairment. I attempted to alleviate her concerns and clearly emphasised the inclusive ethos of the study where critical illness survivors of all abilities were invited to participate. However, from my brief observation and interaction with James I was initially concerned whether the tool-box of methods would be flexible enough to harness his story and whether I had the knowledge and skills to facilitate this. Although I had experience of undertaking holistic nursing care with children with challenging behaviours and communication difficulties, I recognised I was a complete novice in conducting research with this patient group. Moreover, I was particularly concerned that James' story would be dominated by more articulate others. Therefore, I actively and openly engaged with James, James' mother, my PhD supervisors, and experts from the study steering group to gain guidance and support. However, during the study James curtailed my concerns. He explicitly demonstrated his agency over the story; how it was constructed and its form. It was apparent that the toolbox of methods provided a flexible and inclusive platform for eliciting James' experiences and narrative. This was a personal epiphany, as I realised that behind the façade of perceived disability or impairment, with the appropriate tools (cameras), time to develop reciprocity, and support, James was enabled to tell his story.

In addition to navigating James' communication impairment, his conduct during the study provoked personal feelings of discomfort and awkwardness. James' behavioural outbursts exposed me to conflicts of role and identities. I was within James' home as a researcher and attempted to assume an identity that was ethical, inquisitive, and open due to the exploratory nature of the study. However, this

was challenged as James displayed anger, aggression and violence towards his mother and sibling. I could not, therefore, disregard my other identities as a registered professional and as a caring human being. I reflected at the time (in action) and following the event (on action) whether to intervene or not and made the decision not to as I perceived his mother remained in control. Advice and feedback were sought from James as well as his mother to openly develop our mode of interaction. I also sought guidance and support from the steering group, in particular the paediatric clinical psychologist. Strategies were developed to work with James during outbursts of this behaviour. I tried to limit visits to one hour and used a visual timetable (shown in Image 13) to provide a structure to my visits. This negotiated agenda provided a platform for an engaged and meaningful interaction.
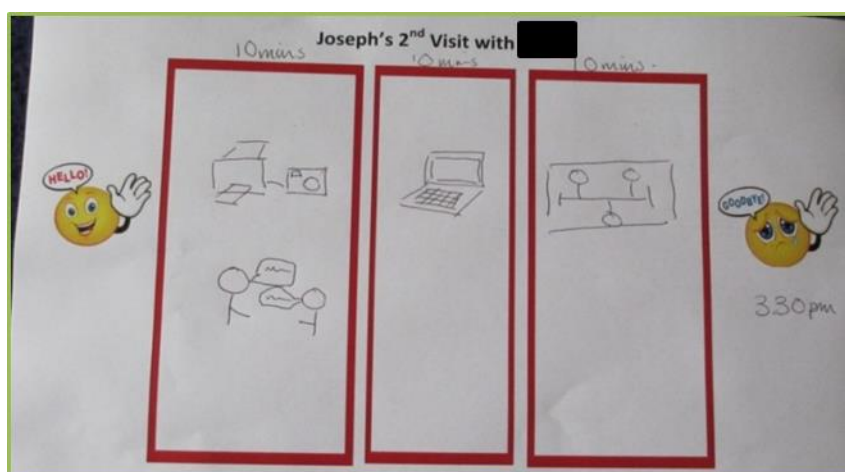
Image 13: Visual timetable (James DCV2)

In relation to James' attachment disorder, I was also concerned about the relationship and potential dependence that may develop during the study. I reflected on this at length during clinical supervision and discussed with the Paediatric Clinical Psychologist strategies to plan my disengagement from James. With the support of James' mother, I began to discuss the study ending with James from my second data collection visit. This appeared well received by James with the final visit being uneventful and not appearing to cause any obvious additional emotional trauma.

5.5   Clare
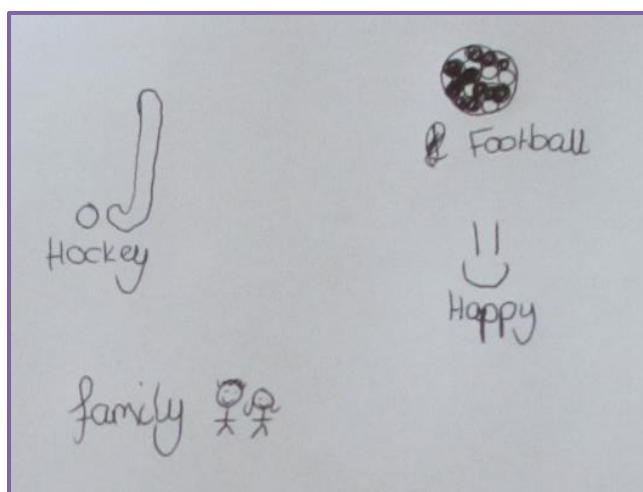
Image 14: Self-portrait (Clare, DCV3)

Clare was born and has spent her childhood in a detached house located in a small village located to the west side of the East Midlands. She lives with her mother, father, two siblings and dog, although her father works away from home during the week. Clare is in year 5 at the local Primary school. On commencing the study Clare was nine years old. Seven months prior to her first data collection visit, Clare became critically ill after experiencing a traumatic head injury. She was initially treated at her local hospital before transfer for neurosurgical intensive care. She was on intensive care for two days and was sedated and invasively ventilated. She received a further five days' care as an inpatient on a children's ward before being discharged home.

Clare had a total of three data collection visits which were conducted at her home after school on a weekday. At Clare's request her mother was present during the first interview but was not continuously present at subsequent interviews.

5.5.1   Clare's story

Clare's story has a dominant positive tone, emanating from optimism and gratitude. However, behind this optimistic façade, elements of trauma and residual disturbance also feature. Collectively Clare's story emanates from positive imagery through a traumatic event and ends with epiphany and enhanced communion, which aligns to a redemptive sequence (McAdams, 2006).

Clare's life chapter one

The first chapter features descriptions of Clare's uncertainty surrounding her accident and critical illness, where she defines these events and experiences as a 'pause' in her life. These unknowns are associated with polarised imagery: gratitude towards the protective nature of not remembering; and the loss and disbelief of being unable to comprehend the chaos that surrounded her injury. Moreover, Clare's critical illness narrative is dominated by confusion. Descriptions of amnesia and the unknown are reported with shock and surprise attributed to her response of being critically ill. However, gratitude appears to pervade within Clare's story as she emphasises her appreciation for surviving the experience.

> 'Clare: *well this is what I heard cause I couldn't remember…yeah. [park's name] it was when it was one day at [park's name] we, me and my friends and my cousin went to [park's name] park and we were just walking round and I was on my roller skates and my sisters and urr yeah just my sister [older sibling's name] and my sister [younger sibling's name] and we were all on roller skates and (cough) sorry umm yeah and we weren't wearing a helmet cause I didn't think that you would need a helmet really cause mum says I was a good enough skater and you know and then there was my sisters and we are all quite good at skating now and then so we didn't really think about putting a helmet on but then all we were doing was skating along and then I remember getting an ice cream it was a calippo shots and then, no one actually seen me fall over it was just me and then there was umm this 14 year old boy called [friends name (m2)] he's one of my friends and he he heard a thud when I had um I was rolling down this hill and then my little sister was holding my mums hand and then my older sister was holding my older cousins hand, I'm not sure, but um yeah and then I went down on my own cause I thought I could do it and then the first time I was fine and the second time my mum had walked on cause she knew I would be okay and then you know cause I'd done it once I would be fine to do it again and then my friend [friend's name (m2)] came down but then he was just a bit before me I think and I had fallen over and then he heard a big thud so he came back and seen me cause he had heard something so he came back at but I couldn't remember this is what I have heard he came back then he had seen me tried I think he had tried to wake me up or something but couldn't cause I had just passed out I couldn't really wake up really so you know he tried to wake me up then he called my mum he really yelled and um cause they thought oh he is just messing about but then they when they had came over called the ambulance and then you know I had been taken in but then yeah you know I couldn't remember anything, but that was a good thing cause I wouldn't have wanted to be through all of that, so you know….*
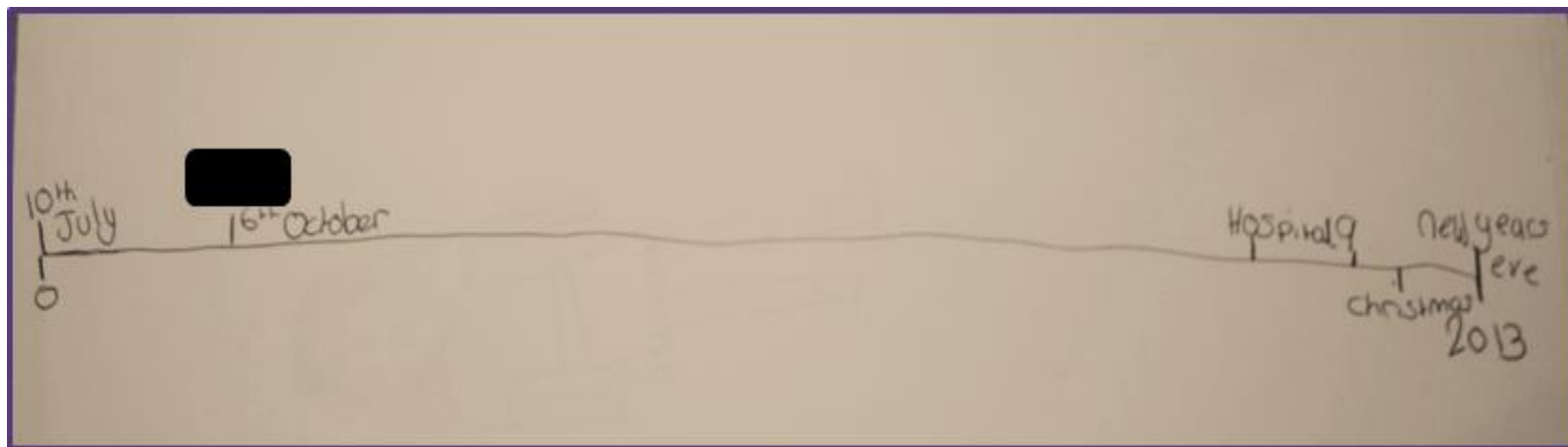
Image 15: Timeline (Clare, DCV2)

> *...Joseph:*   *Okay. So how does it make you feel thinking back about being on intensive care?*
>
> *Clare:*   *well just happy that I got through it all of it and sometimes like just like wow cause like I had no clue what had happened to me it's like waking up on intensive care and then mum saying Clare you've just done this to yourself and then just like wow and you know well I'll be okay really that was my only thoughts then and yeah just looking back now it's just like I'm just happy that I can you know stay here and be okay'*   *(Clare, DCV1)*

Despite many unknowns, Clare constructs a fluent and cohesive story, ascribing these accounts to the narratives of others. She uses the stories from others as platforms for constructing and situating her own, and to address the outstanding information needs she has.

Clare's life chapter two

The second chapter focuses on Clare's rehabilitation in the ward and at home. Despite being set against a backdrop of physical recovery, her story is dominated by negative imagery including traumas, isolation and continued uncertainty.

> *'Joseph:*   *... did you go to a ward after you were on intensive care?...*
>
> *...Clare:*   *...every time I woke up it just I just felt like I was going to cry every single day but then I was alright cause I had some toys to play with and then my mum was there keeping me company but really all I wanted in hospital was my sisters to keep me more company....'*
>   *(Clare, DCV1)*

Clare reports emotionally-laden descriptions of sadness provoked by her containment and isolation on the ward. Although maternal comfort is provided, she yearns for contact with her siblings. Clare's release from hospital is described with positive imagery constructed from her liberation from the institutional and contained environment of the ward and the gratitude at being re-socialised with her siblings and peers.

> *'Joseph:*   *So thinking about this picture of you that you've drawn, how does that person feel?*

Clare:	Happy to be out of hospital.
Researcher:	Happy to be out of hospital, why do you say that?
Clare:	Because, well it was nice in hospital but not nice to know that like my friends were like all outside when I was inside every day. It was quite nice because I was still with my mum throughout the time in hospital, but it was nice to come back home and just like be at home, see my sisters because sometimes they had to go to school and that and it was just my mum.

<div align="right">(Clare, DCV2)</div>

Clare's life chapter three

The final chapter involves Clare's life now, which undulates between stories of changed and unchanged identities. She proposes an unaffected identity since her critical illness and for some of her story Clare takes an anti-nostalgic stance on the past. She alludes to the forward-facing approach to life that she had before her accident, with an attitude of just getting on with it.

'Joseph:	… can you think whether there's any changes that have happened in your life?
Clare:	Well I don't know because it's sort of different because there's like how my life was before, then my accident happened, that was sort of a pause and then it just carried on as normal really. And yeah, it's all okay. Not, I don't think there's any big changes, there's not many changes at all really, but it's still quite the same.
Joseph:	And when you say that your life was on pause, what do you mean by that?
Clare:	Well like it sort of felt like a bit of a break, because obviously I was away from home quite a bit and that was sort of a bit like a pause, and obviously I paused a bit as well. So it was a bit weird but you just get over it and carry on really.'

<div align="right">(Clare, DCV3)</div>

However, this imagery appears to undermine other descriptions in Clare's story of professed changes in relation to her thoughts, memories and behaviours that appear to influence her self- and social identities. Clare interweaves a reflective narrative of her past into her current situation that informs her outlook and thoughts, such as postulating the outcomes of other hospitalised children. This informs descriptions of happiness and gratitude in relation to surviving a near-death experience and being predominantly unharmed. Clare alludes to how this has informed changes to her self- and family identities: she constructs a heightened awareness of adopting safety behaviours to safeguard herself from injury; and the realisation of the severity of the event in enhancing family communion.

5.5.2   Researcher reflexivity

Clare demonstrated openness in telling her story from the outset, evident from her fluency in disclosing certain aspects of her narrative. She was enthusiastic throughout the study and was particularly interested in the interactive activities (e.g. printing out the photos, time-lining activity, etc.). Clare was very keen and willing to engage with the study and we developed a good rapport. During continued engagement, we developed parity evident through Clare's confidence to openly question me.

> 'Joseph: *...Was there anything you wanted to ask me or say to me, that you think was important for this project?*
>
> Clare: *I think maybe why did you feel that you wanted to learn more about how we, how we felt when we left, like how some children felt when we left like maybe what did you, why did you want to sort of learn about how we felt?'*   (Clare, DCV3)

During her initial data collection visit, Clare's mother and siblings were present. Her mother did interject during the interview and was present in the co-construction of Clare's story. However, during the latter stages of the study, Clare's mother and siblings were not involved in the interview encounter as they chose to sit in the other room.

5.6   Steve
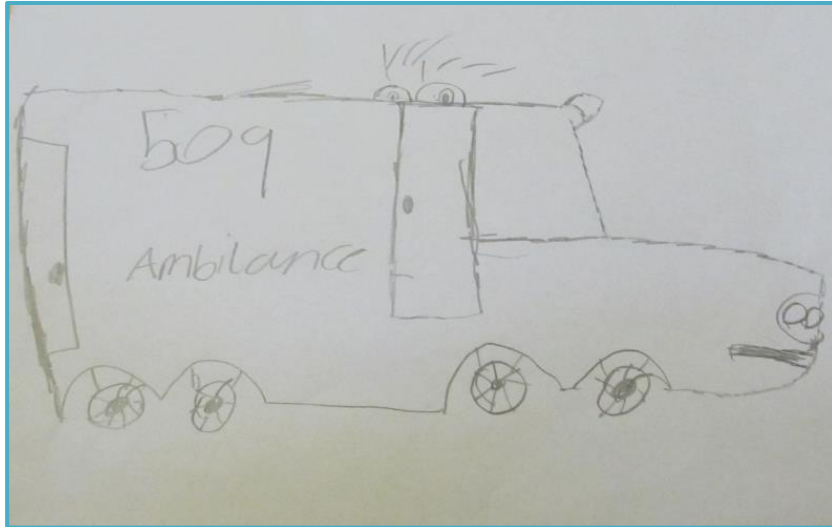
Image 16: Steve, DCV2

Steve lives with his mother, an older and younger sister in a house on a council estate in the north-east of the East Midlands. His parents are divorced and his father resides with his partner. Steve is in year seven and attends a local secondary school. On commencing the study, Steve was 11 years old and had become critically ill due to life-threatening exacerbation of his asthma 12 months prior to his first data collection visit. During this episode he was on intensive care for a day and was sedated and invasively ventilated. During Steve's involvement in the study he was still receiving treatment (medications) and regular check-ups for his underlying conditions.

Steve had three data collection visits during the study which were conducted in his home on a week-night after school. At Steve's request, both his mother and siblings were present during each interview.

5.6.1   Steve's story

Steve's story is largely un-emotive but complex, composed of dichotomous and sometimes competing imagery. Trauma manifests in relation to the control his vulnerable physical health status has over how he conducts his life. However, imagery of opposition through resilience and defiance over adversity faced is described, alongside elements of pity, tragedy, and communion.
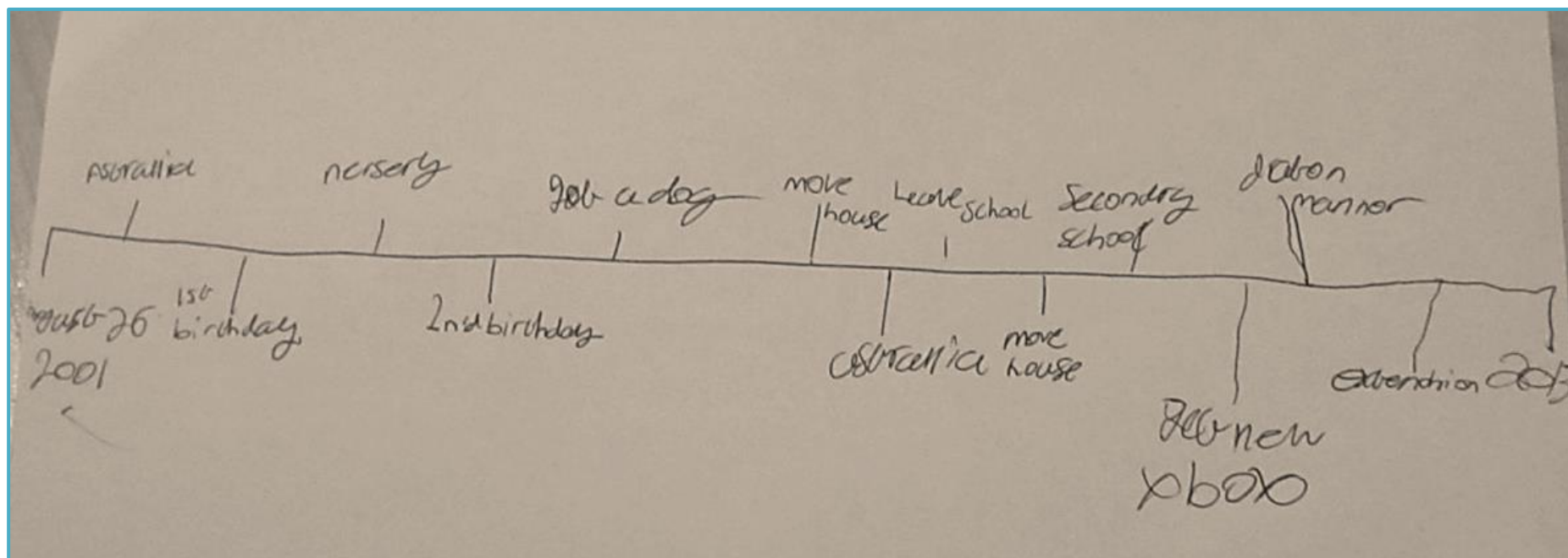
Image 17: Timeline (Steve, DCV2)

Steve's life chapter one

The first chapter involves imagery of before Steve was critically ill, containing descriptions of professed normality and alluding to a 'normally' evolving and ageing identity. The majority of this chapter assumes a positive tone through the reporting of exciting events and activities (e.g. visiting Australia and seeing orca whales), but there is subtle imagery of loss, from parental separation, alluding to the need for comfort and communion. However, imagery relating to his health condition is absent from this chapter, alluding to the perceived low significance of his asthma and allergies in this part of his life.

Steve's life chapter two

The second chapter involves Steve's deteriorating health, critical illness and subsequent rehabilitation including a mixture of negative and positive tones.

Steve reports his deteriorating health using objective and medicalised terminology to describe his vulnerable health status and inability to breathe. Despite notions of oppressed agency over this situation, Steve constructs a story of emotional control, through proclamations of fearlessness despite physical vulnerability.

> 'Joseph: Okay. So what about before you were in intensive care, do you remember that?
>
> Steve's mother: Do you remember the attack that time?
>
> Steve: Yeah but it's not, I don't, I'm not actually scared of it.
>
> Joseph: Okay.
>
> Steve: It's just a bit crazy, not breathing, but I'm not frightened of it.
>
> Joseph: Okay, what aren't you frightened of?
>
> Steve: Me having the attack, because I've done it loads of times.'
>
> *(Steve, DCV1)*

Imagery of confusion and uncertainty about being critically ill and on intensive care also features that emanates from an overriding amnesia. Steve's descriptions of the events, as well as the sequence in which they occurred, are unclear, provoking frustration and conflict with the audience. Even so, Steve interweaves imagery of gratitude of being hospitalised and cared for amongst these negative descriptions.

Following his hospitalisation, Steve reports a rapid transition to home and rehabilitation. He appears to construct a normalisation and is nonchalant about the severity of his experience. This apparent 'playing down' of the experience appeared throughout this chapter, specifically in relation to his personal emotions and interactions with peers.

Image 18: Steve, DCV2

Steve's life chapter three

The final chapter involves Steve's life following his critical illness, and includes conflicting imagery of normality and stability against imagery of transitions, ongoing adversity and enforced change.

In the foreground, Steve alludes to a number of changes in relation to his educational, health and social identities. He aligns this dynamic imagery with caveats of professed normality. Steve poses conflicting descriptions that allude to his perceived social and self-identities. Despite his asthma diagnosis and critical illness being largely omitted from his story, Steve openly defines his physical self as having the 'worst asthma'. He alludes to what he perceives as other peoples' (social) perceptions of having such a physical identity and infers vulnerability, pity and weakness. However, he challenges these perceived social connotations, by constructing a strong self-identity.

> 'Steve: Because I have the worst asthma and it just comes and goes.
>
> Steve's mother: You have days that you're very tired, don't you? It's not just a matter of the asthma attacks; he'll have days where he's just exhausted.
>
> Steve: No, but you know you'd never let me off school then.
>
> Steve's mother: You miss enough time. There isn't many weeks he doesn't miss at least one day.
>
> Steve: No, you send me to school every week.'
>
> (Steve, DCV1)

Descriptions of professed control and calm, even during times of trauma and adversity, are reported. Despite professed control, resilience, and a rehabilitated identity, Steve alludes to the residual negative impact that his critical illness and underlying condition continue to have on his physical form. This manifests in a number of ways through Steve's narrative with imagery associated with: physical vulnerability; repeated exposure to health professionals and interventions; and a dependence on healthcare and medication for survival being reported. This negative impact is not just limited to Steve's physical health. He constructs imagery of the enforced restriction that his physical vulnerability has upon his agency and social identity, dictating and controlling the activities that he is able to undertake and when. Steve's descriptions allude to a more isolated and constrained existence, recognising his difference from his siblings and peers. Sleep disturbances and an undulation between health and illness are associated with tiredness, poor concentration and absence from school.

> 'Steve: I don't really sleep...I do get to sleep but it's either I wake up in the middle of the night and wake up quite late in the day, not late in the day but like 11 o'clock, but I don't wake up in the night and I get up really early...I've been growing...like I said like I wake up really early, I'm not tired. I try to go back to sleep, and

> *I have this urge to like, when I'm lying down I have the urge to go, like to get up, like I can't stay down, like there's somebody pulling a rope, pulling me up.'*
>
> *(Steve, DCV3)*

However, Steve constructs a counter story that alludes to his desire to exercise his own agency. He narrates a quest, mediating between independence and dependence. Imagery of opportunities to exercise his own agency over others is associated with positive imagery due to his perceived control and ownership. Recognising his own limitations and vulnerabilities, Steve utilises other characters (mother, peers and teachers) in his story to enable his independence in order to maintain his social identity through their surveillance, support, and assistance. He does not associate negative imagery or sorrow to this imagery - instead he remains objective and un-emotive in his disclosure.

Steve alludes to his selectivity in disclosure about his illness with peers due to his fear of stigma. This anxiety emanates from the perceived response from his peer group if he disclosed the true severity of his condition, provoking Steve to conceal and contain his experiences from his peers. This imagery alludes to Steve adopting a dynamic social identity that is defined by his audience.

> 'Joseph: So have you talked about being on intensive care with anybody?
>
> Steve: Yeah…I've talked with some doctors. I haven't talked with my friends about it, not much because they'll probably take the mick.
>
> Joseph: Why would they take the mick, do you think?
>
> Steve: I don't know, they're just like that.'
>
> …. 'Joseph: And what do your friends at school think about you having your asthma and?
>
> Steve: Not really like most of my school friends that look after me; it's my friends on here who go to other school.
>
> Joseph: Okay, and so what do the people at your actual school think about, so the people in your class?
>
> Steve: They don't know much. They just, they know I've got asthma but they don't know how bad I am.'
>
> *(Steve, DCV1)*

5.6.2   Researcher reflexivity

Steve initially appeared reluctant to interact and tell his story despite encouragement from myself and his mother. However, during the data collection period, Steve developed an increased openness and rapport. Nevertheless, there

are some aspects of Steve's story where he appeared less confident to disclose. This could be attributed to him not understanding what was being asked, genuinely not knowing what to say due to the abstractness of the topic, or not wanting to disclose. This is particularly evident in responses to enquiries about his emotions as Steve responded by either stating 'I don't know' or retorting with an observation or objective statement. On reflection, the content and delivery of Steve's story could also have been influenced by his adolescent identity or my gender. He may have constructed a story that kept evocative and sensitive imagery hidden due to fears of portraying himself as vulnerable in front of another man.

Steve asked his mother to be present within the room during the interviews. Despite the mother being there to support Steve, it was also evident that she interjected to confirm, refute or elaborate. At times this resulted in Steve responding with frustration, particularly when responses did not align.

I found the interviews with Steve challenging and at times awkward and frustrating. I recognised that these feelings stemmed from my inexperience and insecurities in interviewing closed individuals. Although it is evident from this analysis that Steve provides a complex and very interesting narrative, at the time of the interviews I was concerned whether Steve was being provided with a suitable platform to narrate his story. Despite engaging with different methods, concerns about the superficiality of the data existed, which emanated from his limited responses and closed emotional state. These perceived issues provoked me to contemplate the balance between sensitive exploration and rigorous inquisition (or interrogation). I was concerned that this could arouse negative emotions and disengagement from Steve. Therefore, I chose to position myself in a supportive but sensitively inquisitive role.

5.7   Katherine
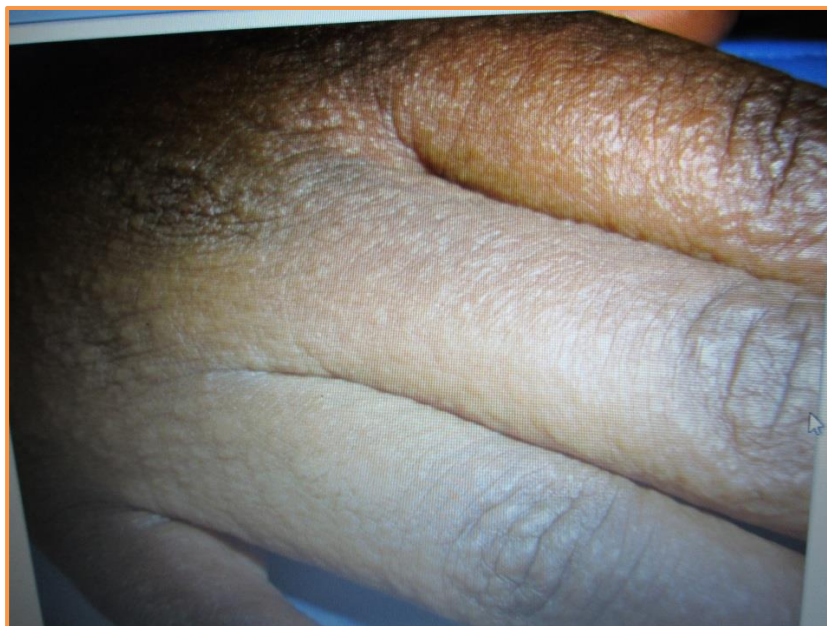
Image 19: Katherine, DCV2

Katherine is a 16 year old who was born and spent her childhood in Zimbabwe in southern Africa. She emigrated to the UK when she was 13 and lives with her mother, stepfather and younger brother. Katherine attends secondary school full time. On commencing the study Katherine was 15 years old and had become critically ill 13 months previously through developing sepsis from a central line, which she had in for treatment of aplastic anaemia. She was on intensive care for four days and was in receipt of multiple system support. During Katherine's involvement in the study she was still receiving treatment (medications) and regular check-ups for her underlying condition for which she had received a bone marrow transplant.

Between the initial visits (information visit and first data collection visit) her parents had separated and were not co-habiting. During this separation, Katherine would reside during the week with her stepfather in the large town where she went to school. At the weekends Katherine stayed with her mother and younger brother who lived in a house located on the south-easterly outskirts of a city in the East Midlands. During the study Katherine's parents reconciled (second and third visits) and they all moved to live in the stepfather's residence.

Katherine had a total of three data collection visits which were all conducted late on a Saturday morning due to her school commitments. All visits, bar one (final visit conducted in local café), were conducted in Katherine's house, in the sitting room.

5.7.1 Katherine's story

Katherine tells a story that is multifaceted and eventful. Despite her story being dominated by sadness, pain and loss, she navigates this adversity by telling a forward-facing, dynamic story. She emphasises her defiance and optimism, aligning the audience's focus to her here and now, and future aspirations. Tones of tragedy, epiphany, redemption and transformation are evident in her story.

Katherine's life chapter one

The first chapter relates to Katherine's upbringing and emigration, with descriptions of a culturally and environmentally different childhood in Zimbabwe (Africa), composed of positive and negative tones. Katherine alludes to her childhood in Africa as liberating and allowing her independence to evolve, through unrestricted play and exploration. However, she describes how Africa is not all positive as she alludes to the deficits in the economy and education systems. She justifies her favouring emigrating to the UK to receive a better education and a higher standard of living.

> *'Katherine: Yeah it was, because here school is more much better. In Africa, like most tribes, you don't really learn that much because in other schools some teachers don't get paid well and they just leave. But here you get school, free school, everything; in Africa you have to pay for school, you have to pay for everything.'*
>
> *(Katherine, DCV1)*

Katherine tells of loss of characters in her story, such as the death of her father in her infancy, with her loss compounded by her lack of memories of him and the absence of maternal contact due to her mother's emigrating to the UK. The non-existence of key characters in her life is not associated with negative imagery - instead she reports positivity in her emotions, building strong attachments, aspirations for a better life, and focuses on re-joining her mother.
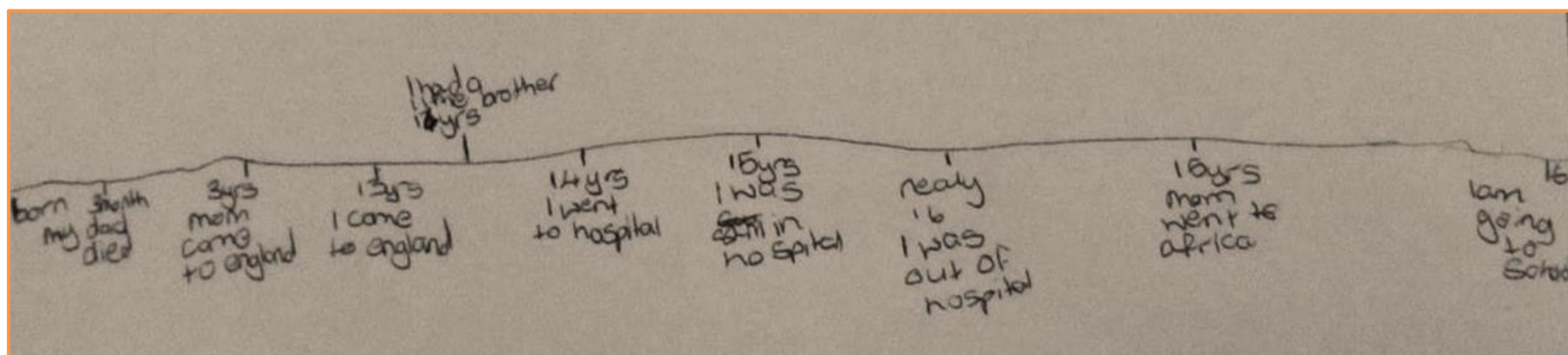
Image 20: Timeline (Katherine, DCV2)

Katherine's life chapter two

The second chapter relates to diagnosis and treatment of aplastic anaemia and her critical illness. Negative imagery represents the physical and emotional trauma Katherine experienced that imposed on her agency and infringed on her social identity.

Katherine begins this chapter by recognising something was wrong, a bodily change, and embarked on a crusade to disclose this to others and ultimately be heard. Characters (educational peers) are used to confirm her belief that something was wrong, but Katherine reports confusion about what was happening to her. Other characters in her story (adults) disregard her when she discloses concerns about symptoms. She interweaves imagery into her story of her own identity that is persistent and determined and demonstrates that she can exercise agency despite apparent maternal disregard. Katherine subsequently constructs a crusade to be heard but is unsuccessful until her condition worsens and additional signs and symptoms manifest, which results in action.

'Katherine: *I used to go to school, I started school in England when I was Year 8 and I was very well, I didn't have any problems. And I was having more fun. When I went in Year 9, like nearly the end of Year 9, that's when I just feel weak, and then just a little bit of blood coming out of my mouth every time. And my friend would say oh Katherine what's wrong with you? And I was like I don't know it's just blood coming out of my mouth. I didn't feel well that day and I just feel weak, and there was like a lot of blood coming out, spitting like more blood from my mouth when I told my mum she thinks I didn't brush my teeth very well. She was just like you have to brush your teeth. And I said I brush my teeth every time. That's when she took me to the dentist. And the dentist says your teeth are very well...I went to the loo and my wee, all the wee was all blood. I told my mum but I flushed it before I told my mum, so I told her and she was like it's just blood... But on my skin it was coming like, you can see blood through my skin, and my throat I just feel something block my throat. I went and had a look in the mirror and I saw these big clots on my mouth, and my throat was like big clot of blood. And that's when I show my aunt and my uncle, I said to my mum did you see that? And my mum said what is it? I showed my mum, that's when she take it serious from then...they said I had to go to [location 4] for my check, they have to check my bone marrow...When I went back to [location 4] they told me I had plastic anaemia which I didn't know what it was. So I asked them what it was and they told me it was like when your bone marrow stop producing blood, so I need a new bone marrow transplant. So they told me to come back after about a week for treatment. I went back to [location 4], to [location 1]. When I went back to [location 1] I went to the fair and I have more fun during the week because I know I was going to the hospital.'*   *(Katherine, DCV1)*

Katherine's admission to hospital and the start of her treatment journey were synonymous in her story. She constructs dynamic imagery, with movement and transitions that reflect the progress and knock-backs that she encountered, as well as the geographical movement required to receive care. Katherine conveys the severity of her condition by describing a lack of essential components in her body which is associated with vulnerability. As quickly as her health status improves, Katherine reports deterioration and becomes critically ill. Negative imagery of how her treatment and interventions left her exposed and susceptible and subsequently rendered her unable to undertake normal activities (such as eating) features in her story.

Her critical illness is reported within this inpatient narrative, with imagery of a forgotten state, which appears to be partially re-formed by her mother's story. However, her mother's narrative provokes negative imagery in hearing how close Katherine was to death. In contrast, Katherine affiliates positive imagery to her psychological and social well-being whilst critically ill. She reports feelings of empowerment, being treated as an individual, and being informed of the consequences so she could make informed choices, upholding her agency. This part of her narrative appears to be during a time of recovery from critical illness, as she confirms near total amnesia of the event, not able to recall any memories whilst she was in receipt of intensive care.

> 'Katherine: ...About like five the same day I was shivering: I was used to heating on because I know if I start shivering it's like high temperature, and I was shivering a lot. And I pressed the bell, called the nurse, and I felt so weak, I couldn't walk or anything. That's when they took me to the high dependency and they said they have to inject me. And I said no because I was in more pain and I didn't know what happened next. I just wake up in [location 4]. The day I wake up in [location 4] I fainted, because I didn't, I couldn't walk, I just wake up and try to get water and then I fainted. And then I woke up the next day. That's when my mum told me that I was in coma for four days, and I didn't know that. I had to like, I started walking, like trying to walk again, and it was like a line infection that causes that, a line infection.'
>
> *(Katherine, DCV1)*

> 'Katherine: ...I went in coma for four days and I was 90% something nearly died, and my mum told me when I woke up, and they thought I had brain damage because I wake up late.

Joseph:	And so when your mum told you about that, how did that make you feel?
Katherine:	Sad yeah, but I don't really like thinking about that, that I nearly died yeah. It was, when it happened it was like we're chatting right now, we are talking family, and then that's when I just start shaking and then one time, I don't remember the rest how, because I was here in [location 1]. Because I was in [location 6] and then I asked them to come to [location 1] because I miss all, but I was in hospital still and then when that happened and then I don't remember the rest of journey, how I get to [location 6]. And when I wake up I couldn't walk.
Joseph:	You couldn't walk?
Katherine:	No, I didn't know that I couldn't walk so I was thirsty, I don't know how come when I wake up, so I saw the water on top and I tried to reach that and I fell over again and I fainted again, wake up the next day. So that's when I first realised I couldn't walk.'

(Katherine, DCV2)

After recovering from her infection and critical illness, Katherine describes a realisation that her current treatment is failing and she requires a bone marrow transplant to survive, proposing a mixture of imagery. Excitement of the potential effective treatment is entangled with negativity and upset due to being informed of the severity of the potential side effects or outcomes. The aftermath of her bone marrow transplant exposed her to pain (headaches) as well as physical changes in appearance and ability. Despite attempting to exercise her agency and optimism over the side effects (resisting shaving her hair off because she wanted to see whether it fell out, which it did), the power of the treatment was rapidly realised. A period of isolation is constructed in her story imposing constraint that infringes her social identity, providing imagery of imprisonment, 'high detention', and separation from others.

'Katherine:	I had my bone marrow transplant. I didn't feel anything really because it was just like blood and bloods, you know, when you're giving blood. After like about two or three days I start having bad headaches, my head hurts a lot, and my face was very swollen, and my hair was coming out. I cut it before it was coming out, because I told my, my mum said cut it off, I say no because I wanted to see if it's going to come out, maybe it might not. But it did, and they cut all of it. So my face was swollen. I couldn't walk, I feel so weak, and it was very horrible. But I didn't get all of the infected things that they told me before; I just have bad headache and very swollen face, that's the main thing I had… I was in isolation so I wasn't allowed to go out. '

(Katherine, DCV1)

Katherine concluded this chapter of her life by calibrating her health status in relation to education and peers, and acknowledging that she was back to normal. However, she also recognises how traumatic this chapter was, identifying avoidance as a mechanism used to cope with the negative emotions associated with it.

Katherine's life chapter three

The third chapter relates to the aftermath of her diagnosis and treatment. Katherine reports how her experiences informed her personal and social identities. However, contradictory tales of change as well as resistance to, or recognising a lack of change, feature. Katherine reports dichotomous identities recognising changes to facets of her psychological and social worlds. She tells how her experiences have given her insights into life, and from this overwhelmingly negative narrative, she indicates epiphany and redemption.

> *'Katherine: ... I think I've changed a lot and I know how life works. You might say you are well but you end up being in hospital again. Yeah I think I've changed, a lot of things have changed really, and at school, you know, some children and some teachers, they all change; everything has all changed now.'*
>
> *(Katherine, DCV1)*

Katherine constructs a story of gratitude and recognises the privilege she has had in receiving treatment and care. Through this she tells of the inequity within the world in relation to the provision of healthcare and uses personal illustrations to eliminate the consequence of this. From this epiphany, Katherine reports her desire to give something back, aspiring to train as a medical doctor and provide philanthropic health services to those in need.

'Katherine: *I've seen some people's lives, how it is, you know, and what I've been through as well, so I've been suffering enough. So I need to have a great life for my own things, I don't have to worry for anything yeah, so I don't have to worry about anyone, all I do is doing my job…To help some people in Africa, like here they don't really know about bone marrows, they don't do that in Africa; actually people die because they don't do that, so maybe if I open something new for people in Africa that would be good to save children in Africa….Because I just want to do something different for people yeah. After all this I've been through, it's more important for me to do something for some people as well. Because someone did something for me, so I want to do something for other people as well, like other person did for me.'*

(Katherine, DCV3)

Collectively, she recognises her past as providing a platform to focus her educational attainment, as Katherine reports this can be used as a currency for agency over her future. She recognises that characters in her story have attempted to restrain or disregard her ambitions. However, she professes determination and copes through avoidance. In contrast, her story alludes to imagery that constructs an unchanged identity in relation to her character and how she is perceived by her peers, but changes to her positioning with her educational peers challenge this imagery. Katherine reports being put back a year and recognises her status has changed. Collectively, she recognises her past as providing a platform to focus her educational attainment, as Katherine reports this can be used as a currency for agency over her future. She recognises that characters in her story have attempted to restrain or disregard her ambitions. She professes determination and copes through avoidance. Questioning by her peers for explanation and their not conforming to how she expects them to behave towards her appear to further infringe on her adolescent capital. Katherine responds with violence in an attempt to re-establish her social capital amongst her peers.

I am ████████████████ the girl who was In hospital for a year and I am a very brave person a person who dosen't like to think of her past a person who likes living a happy life and I am not that kind of a perso who like thinking of her past a lot and being sad I love being happy with people and enjoy my life thinking bout my feature. what I am gonna do when I finish School thats me ████
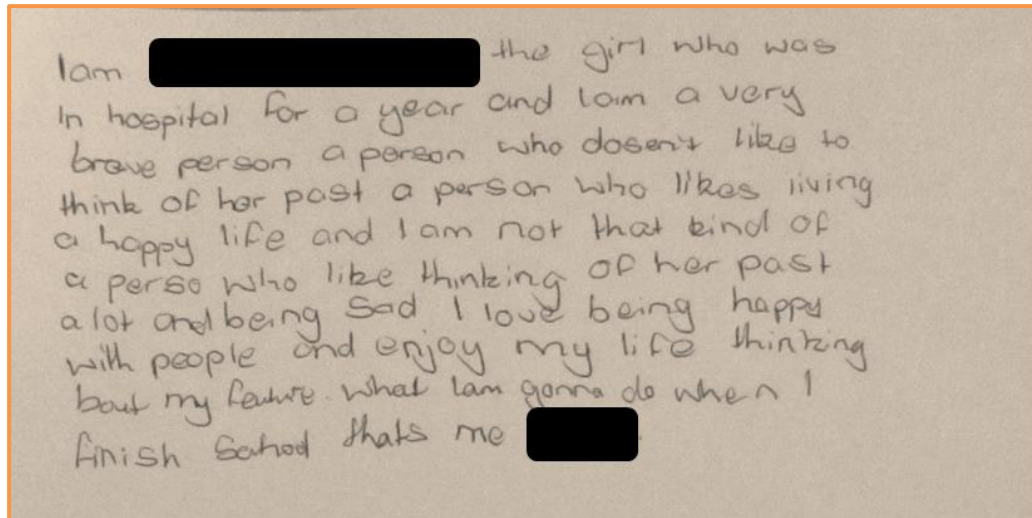
Image 21: Self-portrait (Katherine, DCV2)

5.7.2 Researcher reflexivity

Katherine demonstrated an openness and rapport with me from the outset. She was eager to tell her story, evident from her fluency in disclosing certain aspects of her narrative and from the content of her story (e.g. wanting to write a book of her experience / wanting to go back and tell people). She was articulate even though English was her second language. Katherine preferred to speak with me, as opposed to using other methods from the tool-box even when discussing emotive and potentially complex events in her life.

Katherine's socio-cultural heritage emanates through the content and form of her story. She is aware that her heritage is different from mine and she navigates this difference by modifying the content of parts of her story, through spontaneous rephrasing of certain terms or a willingness to clarify statements when requested.

Only Katherine and I were present during the interviews, although on occasions her younger brother did interrupt the exchange. I approached Katherine's story with great interest and experienced feelings of sadness, shock and pity. Katherine responded confidently and fluently which resulted in my own voice being less (overtly) dominant in the co-construction of her story. When I did respond, to comment or to ask questions, I felt able to explore potentially sensitive/emotive topics due to the reciprocity and parity that we had developed during the study period.

5.8 Andrew
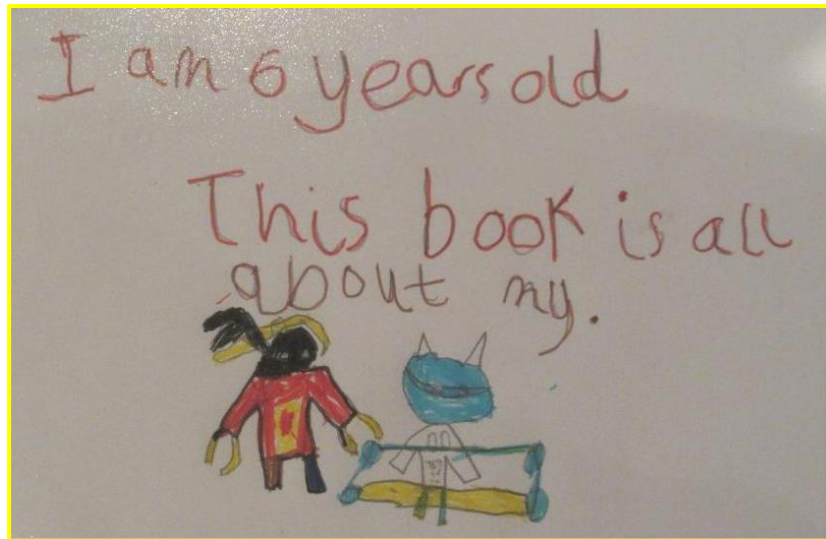
Image 22: Andrew, DCV1

Andrew lives in a house on a private estate in the north-west of the East Midlands with his mother, father and older brother. Andrew was profoundly deaf from infancy and had a cochlear implant from the age of three years. He attends a local Primary school full time.

On commencing the study Andrew was six years old and had become critically ill after collapsing and having a seizure six months previously. He was on intensive care for three days and was sedated and invasively ventilated. During Andrew's involvement in the study, he was still receiving treatment (medications) and regular check-ups for his underlying conditions.

Andrew had only one data collection visit during the study, conducted at his home on a week-night after school. Both his parents and his older sibling were present during the visit. Andrew's visit ended prematurely, at his request, as he became very upset. One month after this visit I received an email from Andrew's father stating that Andrew had requested to withdraw from the study to which I duly agreed. I was initially concerned that his interview had exposed Andrew to negative emotions and resulted in his not wanting to participate in the study. But I was also relieved that Andrew felt able to opt-out of the study and that the systems put in place to enable withdrawal from the study had worked.

5.8.1 Andrew's story

Andrew's story is from one interview and, therefore, predominantly focuses on his life in the present, although there is also reference to both future and past events which were co-constructed with his mother. While the content predominantly informs the tone of Andrew's story, of equal credence is the narrative form. Although not included in other PIC survivors' stories, in order to provide the audience with greater understanding of the interaction, non-verbal responses in the telling of Andrew's story (e.g. 'nodded', or 'started crying') were included in his transcript. These were restricted to observations of physical actions and not the researcher's feelings, thoughts and interpretations.

Overall, Andrew's narrative tone is dynamic, initially appearing positive, interjected with humour and joking but concludes in negativity and trauma. This ending is charged with adverse events and feelings, and the outpouring of negative emotions which prematurely terminated the interview. Even so, Andrew places himself within the narrative as a strong and humorous individual with an evolving self-determination and identity.

Andrew's life chapter one

The first chapter from Andrew's story relates to his deteriorating health and intensive care. Although chronologically this chapter is presented first it actually emanated last in his narrative and was the chapter that required most co-construction (with his mother) when discussing it. Superficially, Andrew provides imagery of an amnesic state surrounding the events and problems in this chapter of his life. Through their co-construction, Andrew and his mother identify traumatic imagery, health professional conflict of roles, and negative emotions.

'Andrew's mother:	*From MacDonald's?. No. and then can you remember when they well you woke up in hospital?*
Andrew:	*Mm*
Andrew's mother:	*What was you thinking when you woke up?*
Andrew:	*don't know*
Andrew's mother:	*Was you happy? Was you scared? Was you frightened? Was you sad? Was you fed up? Was you upset? [signing as she saying the words]*
Andrew:	*Fed up [whispers]*
Andrew's mother:	*what Joseph can't hear you.*

Andrew:	*Fed up...*
...Joseph:	*And what made you feel fed up?*
Andrew:	*Everything*
Andrew's mother:	*Can you remember why you was fed up…*
...Andrew:	*Mmm plasters on my head [saying gradually louder]*
Andrew's mother:	*You had plasters on your head?*
Andrew:	*Yes. A lot.*
Andrew's mother:	*did you have plasters on your head?*
Andrew:	*Yes [laughing]*
Andrew's mother: you	*Were the nurses and doctors trying to do something to you? Can remember?*
Andrew:	*Yeah bandage me up*
Joseph:	*Bandage you up?*
Andrew's mother:	*Bandage you up? What were they trying to bandage you up for?*
Andrew:	*Look like a zombie*
Andrew's mother:	*They were trying to bandage you up to look like a zombie*
Andrew:	*Yeah [laughing]'*

(Andrew, DCV1)

The chapter identifies Andrew's deterioration in health status. Although Andrew's mother interjects and attempts to provide clarification or prompt Andrew to respond, this aspect of his narrative is either forgotten or suppressed. From his deterioration in health, Andrew's story describes a largely forgotten experience of being on intensive care. His disclosure of this part of his story does incite negative and traumatic imagery. He uses the term 'fed up' to describe his overall experience of being on intensive care but has difficulty articulating what specifically made him feel that way. Andrew uses humour in an attempt to cope with this negative imagery. Imagery transposes from negative to traumatic with Andrew's mother posing her interpretation of the events that transpired which depict Andrew being forced to undertake an intervention where he is resistant and restrained. This appears to be exacerbated by health professional inaction as he is frightened, confused and impaired by the health professionals not applying his hearing aids to enable him to hear. However, it is unclear from his narrative whether Andrew confirms this stance as his interpretation of the events. Instead it provokes negative emotions in Andrew.

'Andrew's mother:	*Mmm. Well mummy remembers when you woke up you were upset because the nurses and the doctors wanted to put a mask over your face*
Andrew:	*Mmm*
Andrew's mother:	*And because you didn't have your implants in you couldn't hear what the doctors and the nurses were saying. You got fed up and upset cause you were crying because this mask was over you*
Andrew:	*[starts to cry]*
Andrew's mother:	*It's okay.*
Andrew:	*Don't, don't. [continuing to cry]*
Andrew's mother:	*It's okay, hey. I'm sorry it's okay.*
Andrew:	*I don't like you saying it [continuing to cry]'*

(Andrew, DCV1)

Andrew's life chapter two

The second life chapter is 'living my life now', composed of imagery that is anti-nostalgic, nonchalant, and humorous. Andrew constructs self- and social identities which are strong and have evolving independence. Egocentricity is evident as Andrew struggles to spontaneously identify and locate the importance of other people in his life. This self-identity is formed using imagery of self-determination and strength. His construction is driven by his physical attributes and physical aids to meet his complex needs, which are synonymous with him and how he wishes to be viewed socially.

> *'Andrew:*   *A hat*
>
> *Joseph:*   *A hat?*
>
> *Andrew:*   *A face, a neck, a trousers, handed, arm, leg.*
>
> *Joseph:*   *What's this?*
>
> *Andrew:*   *Body, bag.*
>
> *Joseph:*   *A bag? Your stoma bag?*
>
> *Andrew:*   *Mine'*

(Andrew, DCV1)

Andrew provides conflicting imagery of his educational identity. He recognises his dislike for school and attributes this to the work he has to undertake there. Yet he also associates positive imagery to educational characters including 'friends and play' and 'his teacher'. Although limited descriptions or feelings are associated with his friends, Andrew does attribute his positive imagery towards his teacher who does not over-power him or oppress his agency.

Andrew alludes to his on-going health problems and hospitalisation. He associates negative imagery to the outcome of these events described (e.g. fall off chair = hurt) but he also appears to dismiss or disengage from the content.

5.8.2   Researcher reflexivity

From the outset of the study, Andrew was engaged and appeared comfortable speaking with me. He used a range of methods from the toolbox to convey his story and appeared to enjoy undertaking the graphic elicitation activity. Andrew's story focuses on his current life (day-to day activities, going to school, play, likes/dislikes) which could have been influenced by his cognitive (pre-operational) and psychosocial (Initiative vs. guilt) development (Erikson, 1995; Piaget, 2001). He might, therefore, have had difficulty in conceptualising and articulating his thoughts, feelings and the meaning of past events.

Andrew demonstrated a willingness to tell his narrative mostly through visual methods. His performance varied according to what aspect of his narrative he was telling and who this was constructed with. For example, Andrew demonstrated confidence in narrating aspects of his self-identity, such as his likes and dislikes. However, when discussing aspects of his critical illness with his mother he became introverted and meek. Throughout his interview, Andrew appears to enforce his

power over his audience in making demands as to how they should behave, or who could observe/listen to parts of the narrative.

Andrew's narrative was extremely emotive and challenging and provoked me to critically reflect at length individually, and during PhD and clinical supervision.

Although he uses speech as his main form of communication, his diction is unclear at times and during the interview I had problems understanding certain words. In the story I did ask Andrew to clarify statements to ensure I understood.

Andrew was the youngest participant in the study and I was, therefore, aware that his developmental level (physical, cognitive and psychosocial) might influence how his story was constructed and told. Prior to conducting the interview, I considered my role and that I might have to have greater involvement in the construction of his story. I was conscious of my voice dominating the narrative and so attempted to focus my contribution on probing aspects of Andrew's story to gain understanding as well as provide encouragement and support. Andrew's parents, particularly his mother, also feature in the co-construction of his story as communication adjuncts. This is apparent in a number of ways: to provide clarification when I could not understand certain words or phrases; to adapt my contributions in the interview into more familiar terminology for Andrew; and to use sign language to emphasise certain points.

Witnessing Andrew's trauma, his becoming upset and externalising negative emotions (crying), was evocative and provoked feelings of conflict. Although I believe that I conducted myself ethically and with integrity, it led me to question whether I and the study were an intervention[32] and whether I could have acted differently. Having analysed the transcripts, there were opportunities for me to have interjected and actively supported Andrew to direct his story away from this trauma. However, at the time my rationale for inaction was to minimise the paternalistic and protective dominance of the co-construction. I, therefore, view Andrew's emotive response as integral to his story and by intervening I would have muted this.

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32 Prompted a wider debate for me – although it is professed in the literature that exploratory and interventional research are polarised maybe for participants their experience is the same.

5.9   Mark
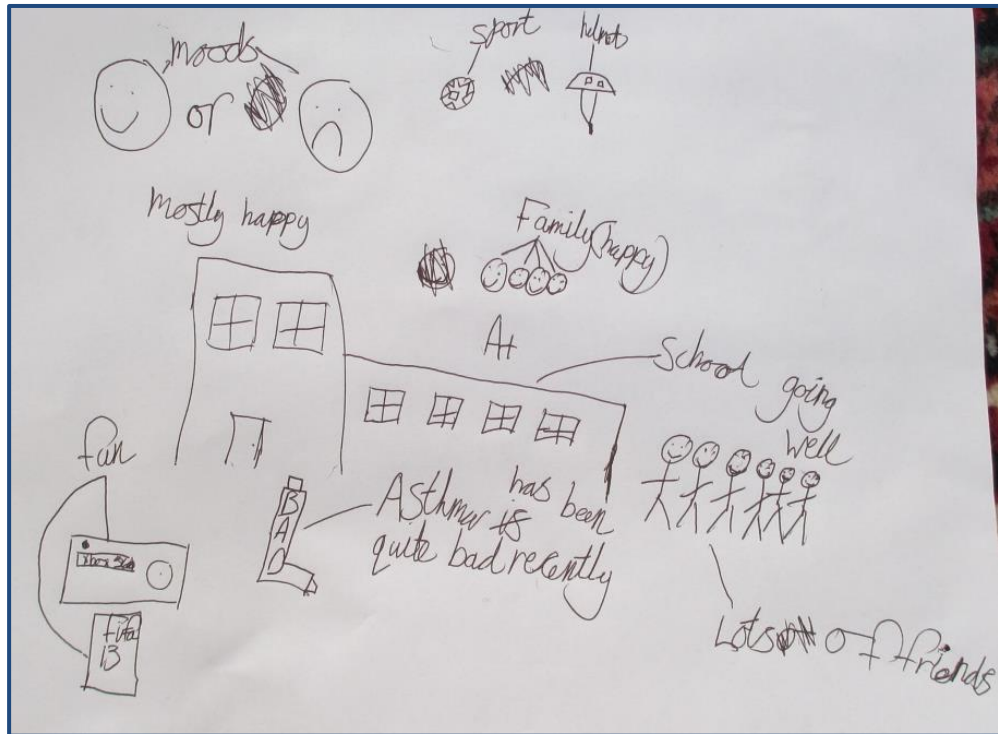
Image 23: Self-portrait (Mark, DCV2)

Mark lives with his mother, father and younger brother in a house in a large town in the south of the East Midlands. Mark attends secondary school full time. He was diagnosed with asthma at the age of five years.

On commencing the study Mark was twelve years old. He had experienced a life-threatening asthma attack 14 months prior to his first data collection visit. He was on intensive care for seven days and was sedated and invasively ventilated. During Mark's involvement in the study he was still receiving treatment (medications) and regular check-ups for his asthma. Mark had three data collection visits over a six month period. Due to illness and family commitments, his first visit was two months after he had consented to participate in the study. All visits were conducted at his home on a week night after school.

5.9.1   Mark's story

Mark tells a story of tragedy and crusade against the adversities that manifest in his life. His emotional, psychological and social journeys undulate with notions of recovery and improvement. Ultimately there is no epiphany or redemption from these multiple adversities as he describes a worsening emotional and psychological

status that cannot be contained. Subsequently, these adversities encroach into his social world, further exacerbating his fears of stigma and ridicule from peers.

Mark's life chapter one
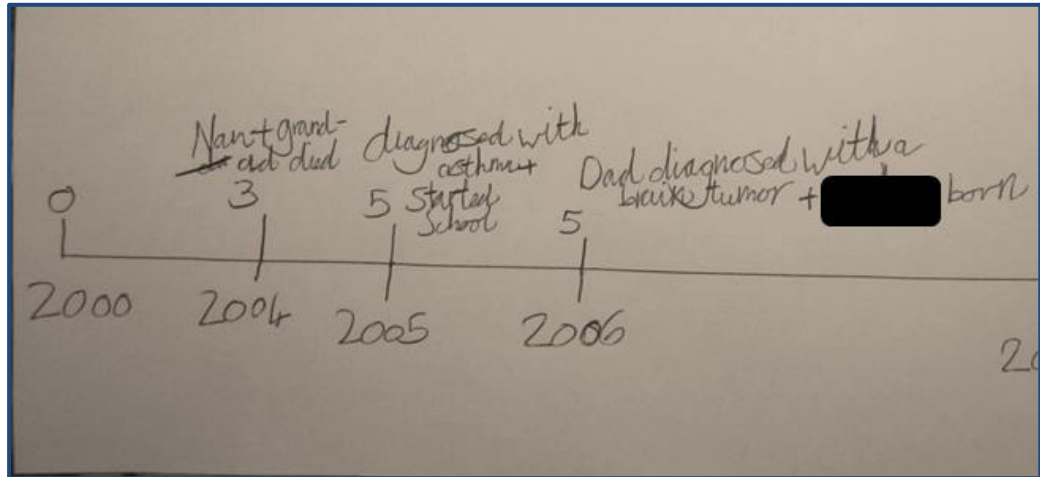
Image 24: Timeline (Mark, DCV1)

This life chapter involves Mark's early childhood. Early in his story, Mark describes his exposure to human mortality through death; his grandparents' death; and his father's diagnosis and treatment for a potentially life-threatening condition. His construction of these events is constrained by negative emotions which emanate from his evocative descriptions and result in an outpouring of physical distress. Mark invites his father to co-construct and support him as he is unable to verbalise some of the narrative. But instead of providing a cohesive narrative it identifies differences in Mark's and his father's perception and recall of events. This provokes confusion and uncertainty around these events and results in a dialogue of disagreement.

Negative emotions appear to originate from associated adversities from this loss of his grandparents. Issues of mistrust with his parents and their explanations of the events (inferred they had gone on holiday) is interwoven into his story. Mark constructs imagery of resentment to his realisation of the permanent nature of their deaths. He interweaves a complex narrative that provokes contemplation of personal ideology and belief systems in relation to death and dying. This provokes additional anxieties as competing dialogues between his desired belief system, its underpinning tenets, and his actual beliefs are posed. These incongruent thoughts and desires appear to render Mark exposed and tormented.

> '*Joseph:*   *And what is it about dying that you worry about, is there anything?*
>
> *Mark:*   *Not being able to live again, because you'll just be nothing, but that's the only thing I worry about, if I'm going to die, but kind of been put at ease lately, because I guess I've gone back to school. It was the holidays when I had a whole day to think about it, and now I'm at school for six hours, when I get home I do my homework, so I have stuff to do to occupy myself, so I'm not as worried about. It's only at night, but at night I just use my iPod for a bit, and that seems to put my mind at ease about it.'*
>
> <div align="right">(Mark, DCV1)</div>

Mark's life chapter two
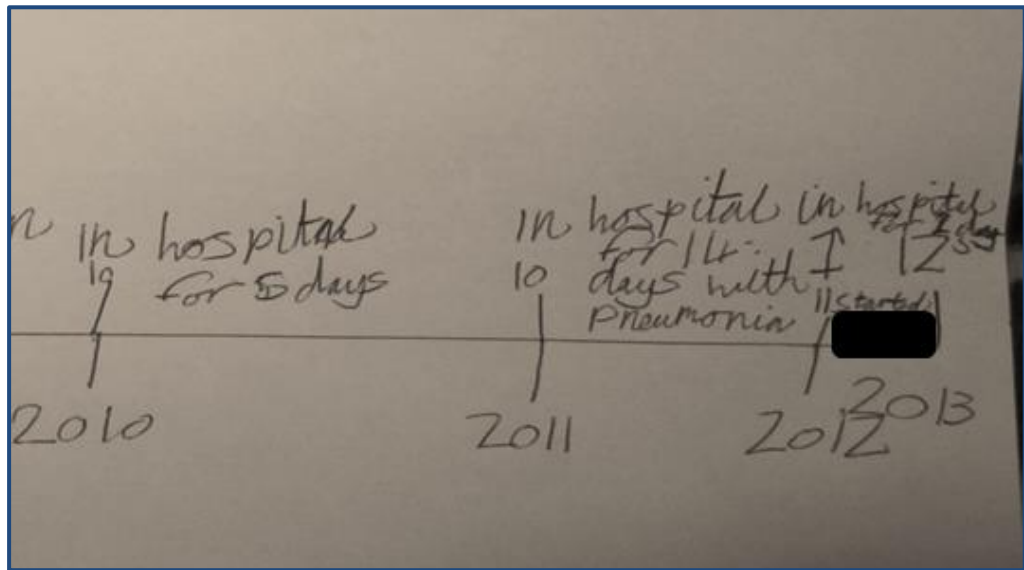
Image 25: Timeline (Mark, DCV1)

Mark's second life chapter focuses on his critical illness and rehabilitation. Imagery of Mark's undulating health status is posed with increasing numbers of acute hospital admissions due to escalating medical needs. Negative imagery is expressed of traumatic and scary scenes and events whilst in hospital, relating to feelings of breathlessness, body failure and medical procedures, as well as of observations of others.

> '*Mark:*   *I was just like I, was pretty weak then and if you get hurt or something, you get weak and it was quite scary and like there was this, when I was first in, when they took me to [hospital 2] before I went up to [location 3], there was an old lady on the ward and she was screaming and screaming, it sounded horrible, and that scared me.'*   (Mark, DCV2)

Mark's critical illness admission and subsequent critical care are missing from his story. It is an unknown and Mark reports uncertainty and confusion relating to this, the order, and occurrence of subsequent hospitalisations.

'Mark: The only thing I remember is the, when I was in intensive care, or was it the high dependency unit? It was in [location 1] I remember, this man, the male doctor, he came up to me and he said that he was going to help me and bring me back to full strength, and then he told me to lift up my leg and I could barely lift it, and then he told me to push his hand up and he was pushing down on my hand, and that's what I remember from being in there. And I remember being incubated, when they put the mask thing on me, you know the mask, that's it.

(Mark, DCV1)

He constructs a story of residual physical and emotional trauma experienced, being rendered weak and impaired from critical illness. Mark defines his critical illness experience as pivotal to his residual psychological adversity, describing anxieties, fixations and sleep disturbances. He reports attempts to exercise his own agency through employing strategies to cope and contain his fixations - however, anxieties continue to manifest.

'Mark: Normal, apart from I get scared easier, easier now of like, I always, bad memory, bad thoughts not memories, of like, say I get a pain somewhere I'll be like oh what's this, it could be this, it could, oh wait it could be this really serious disease, oh no, and then I could die. And I'm a lot more, I think about that a lot more now after I've been in hospital, but yeah, we're trying to sort it out. That's pretty much the only thing that it affects me by, apart from that I'm normal, I'm not scared of doing anything. I do have a bit of a fear of hospital, but I'm not like ooh. I just only want to go if I need to go…..No, just whenever I get a pain. Whenever it, not if it, it's not all the time if I get a pain, but if it's like, if I just get a pain I'm not, but if it's continuous then I'll be like oh! I'm starting to get worried, then I'll, it'll give me this, but no, not if it's just a one off pain. And then I ask my parents if they get them as well, and then it's, then I'm fine.'

(Mark, DCV1)

Marks life chapter three

Mark's final life chapter involves his life now and the future, including imagery of enduring trauma, concealment, conflict and aspirations. Dominated by traumatic imagery, he describes fixations, anxieties and emotional vulnerability attributed to his susceptible health status, and exposure to his own and others' mortality. Mark litters this part of his story with negative emotions and evocative imagery to convey the trauma he continues to endure. Descriptions of severe health issues

occupy Mark's thoughts and render him confused, disturbed, and at times unable to function. The characters in Mark's narrative are his parents (specifically father) with imagery depicting them as adjuncts to coping with anxieties and agents for help.

> 'Mark: Someone coming in for no apparent reason, hurting me or killing someone, or doing something - the fact that I just think oh is there a stranger in our, my house, the fact there's a stranger just makes me quite scared as well…
>
> Joseph: And would you say that this sort of anxiety about somebody in the house, is it something new or different to when I last came?
>
> Mark: Well it's always been for quite a while. Mum would, used to have to at night when I was about seven, she'd have to open the curtains, show me all the walls, say no one could get over that, could they, because they'll have to come through all these gardens, to make me feel safe enough to just go to sleep. But then it like kind of eased off. I'll get scared. If I need to go down to get something, I'll set the alarm and I'll turn off the lights off and I'll sprint up the stairs because it's really dark downstairs, and I'm just scared that someone will be in the shadows or something like that.
>
> Joseph: And where do you think that worry's come from?
>
> Mark: Hospital.
>
> Joseph: Hospital?
>
> Mark: Like I watch, I used to watch crime scene investigation things with my mum, and they were fine up until I was in hospital in 2011, for the two weeks. They were fine up until then, I would never worry really about it then. I'd occasionally but not worry really, and then after that I'd just, I've stopped watching them now with mum, I never really watch them, because I just get too scared about it'
>
> (Mark, DCV2)

Mark constructs polarised identities in an attempt to navigate the psychological adversity experienced. The dominant identity is vulnerable and traumatised and exposes him to destructive thoughts and sleep disturbances impacting on his physical function and confidence. An opposing identity is also revealed that portrays a physically sporty, resilient and 'normal' self.
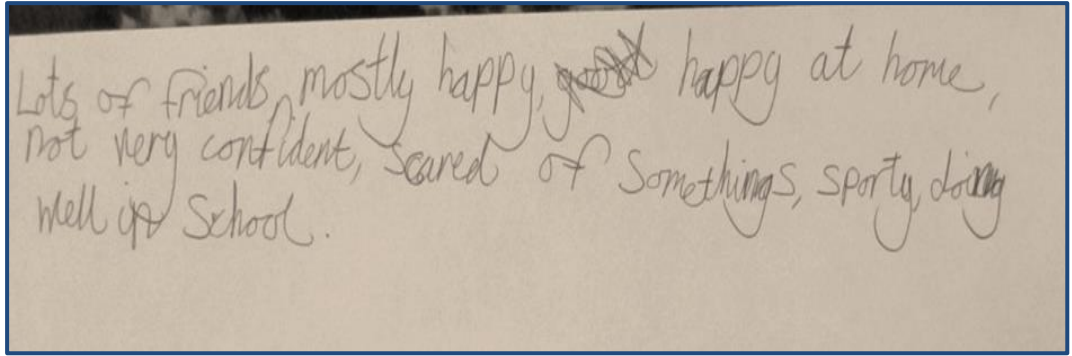
Image 26: Self-portrait (Mark, DCV3)

This identity is formed from the 'normal' activities that he participates in which enable him to be part of the social group with his peers. His desire to conform to this normal identity has further influenced imagery of fears of being stigmatised through the disclosure of his traumatised self to his wider social world (such as his peers). Over the study period Mark develops a realisation that these destructive thoughts are abnormal. However, Mark's attempts to employ a number of coping strategies, such as listening to music, getting a dog, having father co-sleep with him, are ineffective and render Mark unable to exercise his agency over them. His traumatic and traumatised identity becomes more vivid and it is this self that cannot be contained and encroaches on his wider social world.

'Mark:	No, not sleeping well.
Joseph:	Okay, and how do you think that affects you?
Mark:	Tired, don't do as well in sport and school, grumpy, get up late, be late for school.
Joseph:	And how does that make you feel?
Mark:	I'm used to it now, because obviously I don't want to lose sleep but it's just hard for me to get to sleep.
Joseph:	And so does your, are you still having your dad sleep in your room with you?
Mark:	No…No, because then he gets like two hours sleep, so it's not fair.
Joseph:	And so has that made it worse or better?
Mark:	No, it just means I have to, I keep the light on now and use this sometimes [referring to ipod].' (Mark, DCV3)

'Joseph:	And so when you're having these thoughts are they just at home or are you having them anywhere else?
Mark:	In science and RE at school usually, mainly RE but in certain subjects of science, like when we study the stars and the

> *universe. And RE because they're on about reincarnation and that gets me thinking, no other lessons, just them two.*
>
> *Joseph:*   *And so how do you, because obviously it's outside of the home isn't it, and you're obviously amongst other people, how do you deal with that then, you have those thoughts?*
>
> *Mark:*   *In science I ask to go out.*
>
> *Joseph:*   *Right.*
>
> *Mark:*   *But other times I just have to deal with it and continue working, or just blank it out.*
>
> *Joseph:*   *And does that work then, just blanking it out?*
>
> *Mark:*   *Sometimes.'*   *(Mark, DCV3)*

Mark poses imagery of mediating between disclosure and concealment of his abnormal thoughts. Concealment appears to be a conscious decision for Mark in an attempt to prevent his being stigmatised. Peers or school provide a distraction from his psychological torment. Within Mark's family unit his narrative alludes to selected disclosure of his traumatised self. His choices as to what and to whom he discloses information appear to be complicated and undulate throughout the story. Subsequent discussion and disagreement appear to manifest during the telling of Mark's narrative in relation to how informed his parents were/are and lead to Mark attempting to justify his action/inaction. Perceptions of the significance of his experiences at the time of disclosure, as well as the protection of his parents from his worries/concerns, feature as influential in Mark's choices to disclose.

Mark conveys a complexity and potentially incongruent narrative in relation to his events, problems, personal belief systems and future aspirations. A strong and recurrent debate is posed by Mark throughout his narrative in relation to his personal ideology being questioned.

> *'Joseph:*   *So is it the same sort of thoughts that you were having before?*
>
> *Mark:*   *No.*
>
> *Joseph:*   *They're not.*
>
> *Mark:*   *No, different.*
>
> *Joseph:*   *And how are they different?*
>
> *Mark:*   *Before I was just scared of like getting diseases and stuff, but now it's different.'*   *(Mark, DCV3)*

He postulates extensively over his lack of belief system not fulfilling his need for explanation and comfort. This is particularly relevant to his descriptions of death and dying and his need for assurance that there is something after death. His

moral and spiritual beliefs inform his future script and aspirations. Mark's life ambitions focus on his physical and social worlds as opposed to the metaphysical world. He provides imagery of his fears of being alone and uncared for in later life and professes a desire not to be isolated. He stresses the importance of being a social being and having a family around him in the future. However, in contrast to the negative tone that encapsulates this aspect of Mark's future script, he also poses optimistic and hopeful imagery in relation his future. He ascribes a phasic notion to the adversity that he currently endures, professing a desire and an ability to grow out of his traumatic self. He explores within his narrative aspirations to be a professional sportsman and this is narrated without insight or reference to the burden or restriction that his physical health may bring.

5.9.2   Researcher reflexivity

Mark demonstrated an openness and rapport from the outset and which continued to develop through ongoing engagement. From Mark's story it is evident that he is an able communicator although, at times, he did appear to struggle to articulate some of his thoughts and feelings. I approached these apparent difficulties by using empathy in an attempt to engage and support Mark's agency. Despite Mark's story being emotive and traumatic, he was keen to share it,

'Joseph:	*Are you all right, Mark?*
Mark:	*Yeah.*
Joseph:	*Did you want me to stop? No.*
Mark:	*It's all right.*
Joseph:	*Your dad was just saying to me that you get a bit upset about thinking about your Nan and granddad… If you want to have a couple of minutes, or?*
Mark:	*I'm all right.*
Joseph:	*You're okay.*
Father:	*I was explaining to Joseph, Mark, about you saying that you don't remember them or you only remember what we tell you about them, or from photos, wasn't it?*
Mark:	*I remember one thing.*
Father:	*Yeah.*
Joseph:	*And the what, sorry?*
Mark:	*I remember one thing.*
Joseph:	*You remember one thing, what's that?*
Mark:	*When umm [crying].*

> | Joseph: | *It's all right, you don't, if it's too upsetting to tell me you don't have to say anything, all right? Here, have a tissue.* |
> | --- | --- |
> | Mark: | *Thank you.* |
> | Joseph: | *It's all right, you can keep those. And if you want to stop at any time, you just tell me, okay, and I'll stop the tape recorder.* |
> | Mark: | *It's fine, it's fine.* |
> | Joseph: | *It's okay, all right.* |
> | Mark: | *Yeah.'*   (Mark, DCV1) |

Mark's father was present during all his interviews and he appeared to provide Mark with support, certainly during the emotive parts of his narrative. Mark's younger sibling was also present at times during the interviews but would mostly stay out of the room, at Mark's request. During the study, Mark appeared to grow in confidence, speaking openly and depending less on his father to advocate or speak for him. Mark used a range of methods from the toolbox to convey his story.

Mark's story is one of profound sadness and torment, which was evocative at the time of data collection and analysis. It provoked feelings of apprehension and discomfort in me, and led to extensive personal and professional reflection throughout. Mark's story identifies severe anxieties and fixations that appear to negatively impact on his psychological and social well-being. These were evident from Mark's first data collection visit and triggered a number of concerns. I reflected at length about concerns over Mark's involvement in the study exposing him to additional adversity and exacerbating any underlying psychological sequalae that manifested. Uncertainty about my own skills in safely exploring traumatic events with Mark also provoked concern and reflection. I discussed these anonymously with my PhD supervisors, the paediatric clinical psychologist on the study team and at clinical supervision. Guidance and reassurance were gained from these meetings and therapeutic strategies to discuss traumatic events were explored, practised and developed.

5.10 Ollie

Image 27: Self-portrait (Ollie, DCV1)

Ollie lives with his mother, father and younger brother in a house in a large town in the north of the East Midlands. He attends Primary school full time. On commencing the study Ollie was seven years old and had become critically ill after collapsing due to a haemorrhagic stroke. He was in receipt of intensive care for a total of seven days, being sedated and invasively ventilated for five of these. Following PICU, Ollie received a period of rehabilitation on a ward due to the residual ipsilateral paralysis/weakness he experienced.

During Ollie's involvement in the study he was receiving check-ups and health professional support for his residual physical impairment. Ollie had a total of three data collection visits which were conducted in the lounge in his home after school on a week day.

5.10.1 Ollie's Story

Ollie's story has a mixed tone, interweaving imagery of residual and newly manifesting traumas and adversities into a pragmatic and 'getting on with life' dialogue. Ollie places himself within the story with genres of tragedy, epiphany, trauma and transformation. These evolving genres form an overriding redemptive sequence. However, elements of ongoing adversity moderate this transformed tone.

Ollie's life chapter one

The first chapter involves Ollie's critical illness event and subsequent intensive care admission. He constructs a narrative of his prior life which is largely unknown, provoking negative imagery ascribed to the loss of the memories. Despite this unknown, Ollie details his physical deterioration preceding his critical illness whilst at football practice. A profound deterioration in his own condition coincides with his loss of memory and absence in his narrative. Although Ollie identifies negative imagery to his biographical disturbance, he does not relate this to the trauma of forgetting or the deterioration in his condition. Instead he talks about how his acute illness restricted him from being able to undertake an activity that he really enjoys (football).

'Ollie:	*I was pretty happy with it, and it just was like a nice life, and I can't remember much more.*
Joseph:	*Okay, and what was nice about your life before being in hospital?*
Ollie:	*Well I was allowed to play football since four plus, and it was very good. And I can't remember any more much.'*

(Ollie, DCV1)
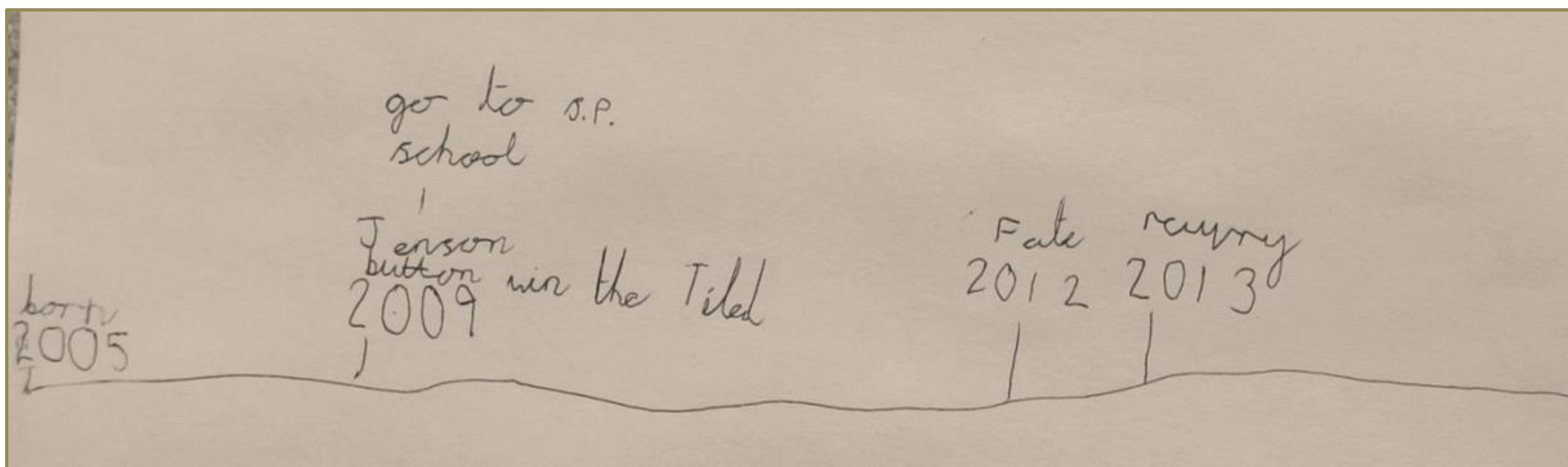
Image 28: Timeline (Ollie, DCV2)

> *'Ollie:*   *Well I think my memory's gone a little bit. If I went as far back*
> *as I went before my accident I couldn't really remember what*
> *happened, last thing was just getting changed, and then couldn't*
> *remember anything else. And I can't really remember which*
> *month you came on your last visit, so I think my memory's*
> *actually gone a little bit….It makes me feel a bit sad.'*
>   *(Ollie, DCV3)*

This unknown originates from his 'fainting' episode (or illness event) and continues in his narrative until he wakes up in hospital. Uncertainty and sadness coexist within this facet of his narrative. Ollie also describes imagery with this event that infers an epiphany. He describes how the opening of his eyes signified a time of realisation that he was able to undertake activities (e.g. opening eyes) that he doubted he would be able to do. Ollie associates the term 'miracle' with this event, thus ascribing his outcome to some supernatural or unexplained power.

> *'Joseph:*   *So what sort of, how does it feel thinking back about this that's*
> *happened in 2012, fainting?*
>
> *Ollie:*   *Really sad.*
>
> *Joseph:*   *Does it, why is that?*
>
> *Ollie:*   *Because I felt really sad and I didn't know what was going to*
> *happen to me, so when I woke up I thought it was a miracle.*
>
> *Joseph:*   *Right, why do you think it was a miracle?*
>
> *Ollie:*   *Because I thought I would never open my eyes again, and never*
> *move one of my body parts again, not with my right hand side.'*
>   *(Ollie, DCV2)*

Ollie's life chapter two

The second chapter involves imagery of his hospitalisation and the initial stages of his rehabilitation. Ollie reports a prolonged hospitalisation following his critical illness, identifying an undulating recovery and vulnerability in health status. He describes his level of disability/ability as a calibrator of where the narrative element fits within his overall recovery.   Ollie associates negative imagery and residual sadness with the trauma of the painful interventions he was (and continues to be) exposed to whilst in hospital. He recognises the failure of health professionals in minimising his pain experience. Ollie constructs a bodily change which is part of a newly defined (recovering) identity.

> '*Joseph:* So thinking about this recovery, what does that involve?
>
> *Ollie:* It involves trying to get, trying to do my football again, starting a new sport, tennis, and seeing you.
>
> *Joseph:* And how have you found that?
>
> *Ollie:* Quite difficult.
>
> *Joseph:* And why has it been difficult?
>
> *Ollie:* Because I still can't really not 100% on tennis with my backhand, because of my right hand.
>
> *Joseph:* And why is that, because of the weakness?
>
> *Ollie:* Yeah.
>
> *Joseph:* And what about your football?
>
> *Ollie:* Yeah, I think my football's alright actually, I don't think there's much problems, but dad says that there's only one problem that I couldn't kick it as hard as I used to.
>
> *Joseph:* What do you feel about thinking back to how you were before you were poorly and now?
>
> *Ollie:* Well I'm a bit proud of myself, what I've been through and how I've recovered. I think that's all…that one was Club Man of the Year so I think the reason why I've got that one, because when I was poorly and I was still recovering I still joined in but I wasn't allowed to play the competitive matches, but I still joined in.
>
> *Joseph:* And how did you join in?
>
> *Ollie:* When we were doing all the skills and stuff, I just came on the pitch and did all of the skills and stuff.
>
> *Joseph:* Brilliant.' (Ollie, DCV3)

Positive imagery is posed, associated with his social connection and support received from other characters, particularly his peers. Peers, namely school friends, are constructed as providing support and encouragement to Ollie despite being geographically separated from him.

Ollie's discharge from hospital is significant in his recovery, inferring a transitional phase. He constructs a post-critical illness identity with notions of physical disablement and restraint. Ollie describes segmented imagery of himself from that of his disabilities, referring to the restriction (own ability and paternalistic) from engaging with the activities of his former self. However, he

also constructs a counter narrative that professes resilience and determination to overcome his physical barriers.

Ollie's life chapter three

Image 29: Ollie, DCV3

The final chapter involves imagery of his life now. Narrative descriptions include 'normal' everyday events and activities. Interwoven within this positive imagery are the manifestation of residual physical disability, ongoing health needs, and the recognition of a changing existence. He poses descriptions of being different from his former self as well as from his peers. This is associated with negative imagery because his own aspirations and desires to function do not align with his physical ability.

> '*Joseph: Okay, and do you think your life has changed since you've been in hospital?*
>
> *Ollie: Yes.*
>
> *Joseph: And how has it changed?*
>
> *Ollie: It's like really, it wasn't as good as it like used to be, it was like I, it's like I can't, when I run I can't do too much balancing but I can run.'   (Ollie, DCV1)*

Ollie recognises the emotional impact of his recovery. He expounds within his narrative the worries that his expectations to assume 'normality' are not realised.

However, Ollie constructs self-determination over his constraining disablement. He poses a story determined to 'normalise' and achieve his former abilities with varying success, mediating between struggle and achievement. He expresses a self-critical dialogue, which recognises his own limitations and openly expounds these, alongside a 'do your best' mantra, which demonstrates a rallying despite facing adversity.

Ollie constructs a realisation that he is different from his peers. He alludes to the subtle exclusion experienced that becomes more apparent over the study period. Ollie recognises his own situating within his social world, which is wider than his peers'. He reflects on the possible social injustices and builds within this part of his narrative an identity that conforms to a privileged status, comparing his resource-rich life against their lack of resources. Moreover, Ollie alludes to the value of human life. He recognises that the outcome of people living with a lack of resources can result in death.

'Ollie:	*...and probably the ones that like [unclear 00:45:37], probably really poorly, no money and they can't get, can't drink and they like die probably...Like people in Africa can't survive because there's not much water sometimes, and sometimes some people get caught in floods and die. And like the ones that live in all of the hot countries that really can't get enough water for their bodies.*
Joseph:	*And why are they important to you?*
Ollie:	*Because they die and I don't like it much.*
Joseph:	*And do you think about those sorts of people much?*
Ollie:	*Yeah, a lot.'* (Ollie, DCV1)

5.10.2 Researcher reflexivity

Ollie was articulate. From the outset of the study he appeared comfortable and confident when speaking about his life. He used all the tools in the tool-box of methods to tell his story, although he did find drawing and writing at times difficult due to his upper limb weakness. Ollie openly reports his involvement in the study and his interaction with me as part of his recovery process and rehabilitation. He, therefore, infers his position in relation to the audience (me) as a reciprocal interaction.

Ollie's first two interviews were conducted in a room where his father, mother and younger sibling were present (periodically). Their presence provided an

opportunity for confirmation as well as disagreement in relation to the content of Ollie's story.

I was at times surprised at some of the imagery that Ollie reported within his narrative, in particular Ollie's narrative content that alluded to the social injustice in the world and the suffering of others in different countries. It caused me to reflect on how I conceptualised children and their perceptions of their world, as his narrative challenged an egocentric notion of young children's development. In addition it gave insight into the receptiveness of children in world current affairs and the evocative nature that certain topics may have on them.

5.11   Chapter summary

Nine unique stories (summarised in Table 15, page 179) have been re-told in this chapter that provide insights into the lives and storied experiences of the PIC survivors that participated. A diverse range of live events, imagery and themes within these stories demonstrates variance of experiences amongst the sample. The next chapter will explore the situationality of these stories against those of significant others through within-case analysis.

Survivor	Life chapter one	Life chapter two	Life chapter three	Dominant narrative genre(s)		
Tim	Becoming ill and diagnostics	Being in hospital	Life now –no change	• Redemptive		
Sarah	Life before I had asthma	Asthma attack, critical illness and rehabilitation	Living with a chronic condition	• Epiphany • Crusade	• Trauma	
James	Before I was ill	Hospital, ward and home	Living now: my quest for normality	• Dissociated • Redemptive	• Transformation • Constrained	
Clare	Head injury and critical illness: an unknown experience	Transition to the ward and rehabilitation	Living life now: more safely	• Trauma • Communion	• Epiphany • Crusade • Redemptive	
Steve	A normal life before	Deteriorating health, intensive care and rehabilitation	Life now	• Trauma • Redemptive	• Tragedy • Communion	
Katherine	Growing up and emigration	Diagnosis, treatment and critical illness	The aftermath of treatment and getting back to 'normal'	• Trauma • Redemptive	• Optimism	
Andrew	Deteriorating health and intensive care	Living my life now	-	• Trauma	• Redemptive	
Mark	My childhood	Critical illness and rehabilitation	Life now and the future	• Tragedy	• Crusade	
Ollie	'Fate' and intensive care	Hospitalisation and rehabilitation	Living life now: still rehabilitating, changed function and identity	• Tragedy • Epiphany	• Trauma • Transformation	

Table 15: Summary of narrative psychological analysis from PIC survivors

Chapter Six

Findings: The re-storied narratives of significant others within survivors' lives - exploring within the case

6.1   Introduction
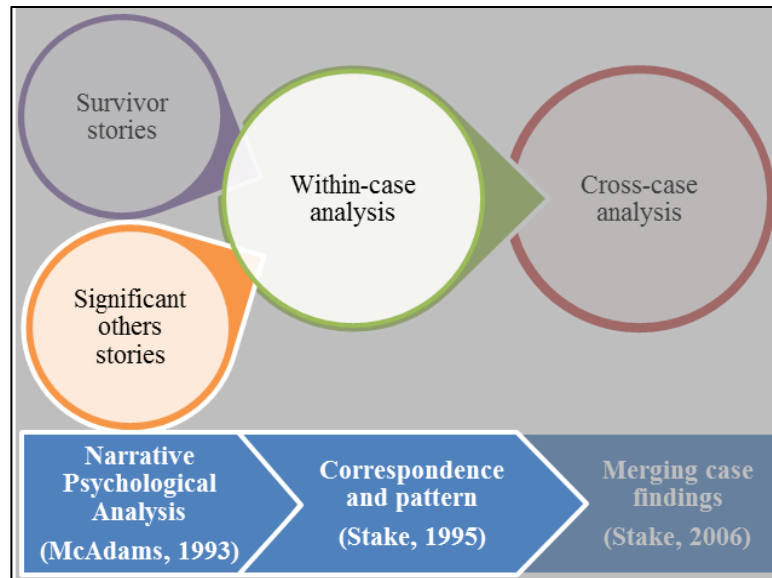
This chapter presents the findings from the analysis within each of the nine case studies. Each case study will be presented sequentially, by outlining the 'significant others' from each case. From the narrative psychological analysis of these stories, a synopsis will be presented which expounds their life chapters, themes and genres. These stories are compared and contrasted with the survivor narratives (presented in Chapter Five) to culminate in within-case themes.

6.2   Case study one- Tim

Tim identified his mother, father and sister (10 years old) to participate in the study, highlighted in Image 30. All consented to be involved and interviews were conducted in the family home. Tim's mother and father requested to be interviewed together whilst both Tim and his sister were present. Similarly, Tim's sister requested that both Tim and her parents be present during her interview.
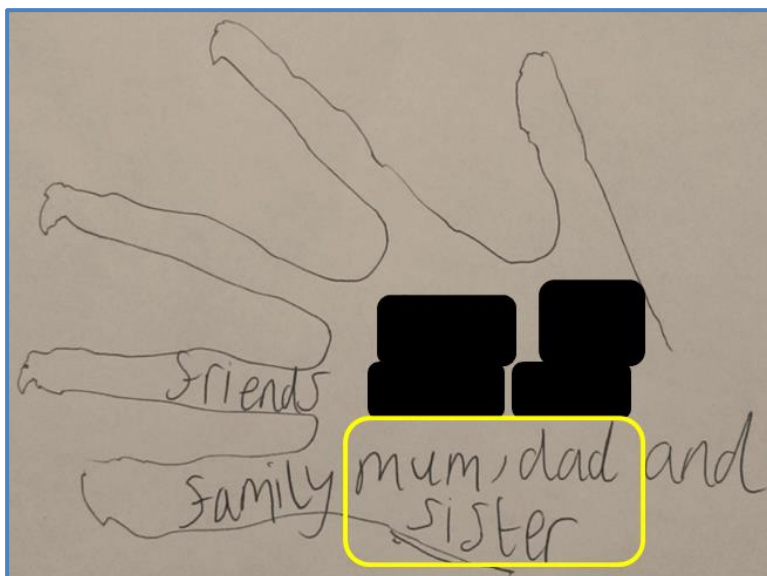
Image 30: Hand drawing identifying the significant people in Tim's life

6.2.1 Tim's mother and father's story – a synopsis

Tim's parents' story is traumatic and emotive and focuses on the significant individuals, their children and themselves, within their family unit. As identified from the following excerpt, historical events and problems encountered as a result of Tim's ill health provoke imagery of fear, sadness and emotional trauma:

> *'Tim's mother:* *Yeah 2010 he had his tonsils removed, and we thought that would be the end of his throat problems, but it's not because obviously what happened last Christmas. So yeah, he's always had main problem with his throat…*
>
> *…Tim's father:* *Yeah, his health has suffered. I hear myself talk quite frequently and our big one doesn't seem to suffer with health as much as Tim….four or five years ago we had a period where there were significant lumps in his neck, and we took him to [hospital name] because the doctor had given us some concern about symptoms being similar to quite a serious blood disease and it got us worried…he has seemed to suffer with his health from the day he was born. Just seems that his immune system isn't fully, he gets everything, so it's a big worry.'* (Tim's Parents)

Within their story, they reflect on themselves as parents and how their experiences have guided their decisions and approach to raising their children, by stating:

> *'Tim's mother:* *…And especially after what happened last year you just want to wrap him up and protect him and look after him, like I was saying about football, being cold, wanting to play outside because he just seemed to get cold, you know, if he's been subjected to that kind of weather and just want to protect him don't we and look after him…*
>
> *…Tim's father:* *I think we're protective parents anyway but it's made us overprotective towards him, we wrap him in cotton wool a lot more now…Well, for the likes of yesterday we had a phone call, he wasn't particularly well in the morning, got a cough, and he went to school, he wanted to go to school. [mother's name] got a phone call to say his health had got a little bit*

> *worse during the day, picked him up and you originally think well want to keep him in, we don't want anything we went through last year, want to keep him in four walls in front of the fire, wrap him up and give him his antibiotics or give him his Calpol, and straightaway it was football, no, not happening, not happening!'*
>
> <div align="right">*(Tim's Parents)*</div>

Positive imagery in relation to their love and devotion for their children is posed against descriptions of sadness, regret, guilt and anxiety. Overall, their story transposes into three main life chapters: Tim growing up and health concerns; Tim's deteriorating health and critical illness; and rehabilitation and residual trauma.

6.2.2 Tim's sister's story – a synopsis

Tim's sister's story is reflective. Although she identifies aspects of sadness, trauma, and separation, she professes an unchanged and normal existence, by saying:

> *'...Joseph:*   *And when Tim came out of hospital, what was life like then?*
>
> *Tim's Sister:*   *Just the same but for a couple of weeks he was still a bit poorly, so we still had to look after him a little bit, but then he was back to normal and just did the same as we do now, like play and things like that.'*
>
> <div align="right">*(Tim's Sister)*</div>

She reflects on the disruptions encountered which were exacerbated by the enforced separation from Tim and her parents, whilst he was hospitalised:

> *Tim's Sister:*   *Well when Tim was poorly, on Christmas Eve umm I was in bed, and then that day we got tickets to go and watch a pantomime, but Tim couldn't go because he was in the hospital, and my mum and dad couldn't either…then I went to see Tim on, no I went with my granny and granddad on Christmas Day, and they went to see Tim but I wasn't allowed, and then he came home on Boxing Day, and then I came home with him to open his presents with him, and just like help him and just stay with him to be honest.'*
>
> <div align="right">*(Tim's Sister)*</div>

Despite Tim's critical illness featuring in her oral story, it does not feature in her timeline (Image 31). She does, however, identify herself as a care-giver and social agent supporting Tim's functioning within his family and wider social worlds.
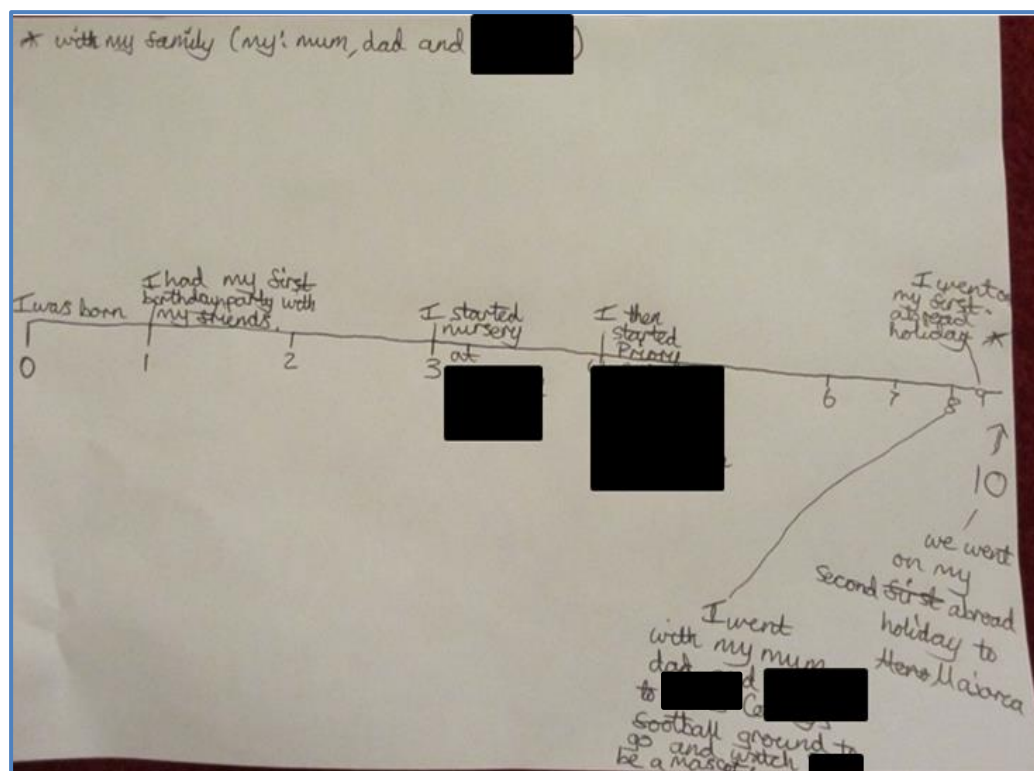
Image 31: Tim's sister's timeline

From Tim's sister's story three life chapters emerged: Tim's illness and hospitalisation; Tim's rehabilitation; no change and emotional avoidance.

6.2.3 Within-case analysis

Themes	Sub themes	
Significance of the time of year of illness	• Annual reminder (anniversary)	• Tim / Parents/Sister
Familial disruption	• Imposed separation • Paternal identity challenged	• Tim/Sister • Parents
Residual impact on emotional and psychological well-being	• Variation in perceived emotional and psychological impact • Fixated on health status • Shared experience, shared dissociation: Avoidance of engaging with potential trauma associated with experience	• Tim / Parents / Sister • Parents • Tim / Parents / Sister
Mediating between protection and restriction	• Exploration of newly defined identity and parenting priorities • Oppression of exploring thoughts and feelings • Information needs	• Parents • Parents / Sister • Tim / Parents / Sister

Table 16: Case study one within-case analysis

Within-case analysis of Tim's story (section 5.2.1, page 109) and his significant others, converged and diverged in relation to tone, life chapters and genres. Collectively, four themes were identified, outlined in Table 16 (page 183).

Significance of the time of year of Tim's illness

Imagery surrounding the time of year, the festive period, of Tim's critical illness is dominant in all three stories. For Tim, this theme involves an ego-centric focus with imagery relating to his illness, inhibiting his enjoyment of the occasion. The adversity and sadness that are associated with this imagery appear to be resolved by Tim's receipt of gifts following his hospitalisation.

In contrast, his sister's and parents' stories describe how Tim's vulnerable health status and critical illness inhibit familial togetherness during the festive season, evoking loss and grief. This appeared to have greater gravity in Tim's parents' story who reported feelings of guilt, failure and loss. Furthermore, for Tim's parents' story the festive season acts as an 'annual reminder' of a formally joyful time of year that has been tarnished by negative experiences and emotions. This annual reminder arouses fear and is used to inform their health beliefs and how they care for Tim. They believe he is more vulnerable during the winter and requires greater protection.

Familial disruption

The second theme, familial disruption, appears to manifest differently between the three stories. Tim's story omits imagery of disruption whilst he was critically ill and hospitalised, and instead describes amnesia and family stability throughout.

In contrast, disruption manifests in both his sister's and parents' stories. Imposed separation from her parents and Tim dominates Tim's sister's story and is associated with dynamic imagery, disruption and isolation. Despite using un-emotive imagery, she infers how this disruption exacerbated her lack of understanding around Tim's critical illness and exposed her to uncertainty.

Similarly, Tim's parents' story describes how Tim's critical illness exposed them to separation and family disruption. In contrast to Tim's and his sister's stories, they describe dichotomised imagery of being torn between their children,

provoking feelings of numbness, disappointment and guilt. They report attempts to keep their family together during this time of uncertainty and chaos but this rendered them physically and emotionally fatigued.

Disruption following Tim's critical illness also appears in their story. Descriptions of the dynamic care-giving roles and identities appear to be re-defined by navigating their emotional, physical and supportive journey. Furthermore, Tim's father's story specifically identifies how the critical illness experience rendered him unable to control his emotions. This challenged his perceived patriarchal identity and re-defined how he conducted himself within his family unit, such as not externalising negative emotions in front of his children.

Residual impact on emotional and psychological well-being

The third theme, residual impact on emotional and psychological well-being, manifests in all three stories.

Tim's story identifies a critical illness event that is predominantly forgotten, although he describes the events, his observations and feelings that surround it. He does not associate negative imagery with these descriptions and when identifying important aspects of his life, his critical illness is omitted completely. This is reflected in both Tim's verbal and visual story, which constructs an unchanged identity. His story is dominated by the present or future scripts with only negative imagery being associated with being inhibited to engage with sports during his recovery.

Similar to Tim, his sister's story identifies in detail the events that surrounded Tim's critical illness and her experiences. Despite being exposed to adversity, her story reports an unchanged emotional and psychological status, unaffected by the critical illness event. In the same vein despite some initial period for recovery, she perceives Tim has fully rehabilitated to his former self.

In contrast, Tim's parents' story identifies residual impact to their emotional and psychological well-being that includes fears, anxieties and emotional trauma. The maternal construction of the parental story appears more open in relation to the residual effects that Tim's critical illness has had upon their joint narrative. Imagery of psychological trauma manifests throughout their story, evident in past,

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present and future imagery. Residual fears associated with future script and the possibility of Tim's physical health deteriorating appear throughout their story.

A shared response in coping with the residual adversity was evident in all stories as they did not engage with the critical illness experience. Tim and his sister conform to a passive-avoidance surrounding the event. Tim's parents' story, by contrast, includes active-avoidance from the thoughts and memories that surround Tim's critical illness in the belief that engagement may be traumatic for themselves and their children.

Mediating between protection and restriction

The final theme, mediating between protection and restriction, manifests in all three stories. Tim's story identifies his parents as significant in protecting and maintaining his health and well-being, with their encouragement essential to achieving his ambitions. This is echoed within his parents' and sister's stories as they also recognise the fundamental nature of support and protection. However, for his parents, this exposed them to uncertainties in the decisions they made. Parental decisions were governed by what was perceived to be best for Tim. Fixations on physical health heightened concerns and provoked overprotective behaviours. They recognised that their parenting style had changed. They were more relaxed in relation to Tim's behaviour but more protective with his physical health, governed by his critical illness.

6.3   Case study two - Sarah

Sarah nominated three significant people in her life to participate in the study: her 'mummy', maternal grandma and paternal gran, shown in Image 32 (page 187). Both her mother and grandma consented to participate in the study, with interviews conducted during the daytime in their homes. However, at Sarah's mother's request, her paternal gran did not participate in the study due to concerns over her deteriorating cognitive capacity.
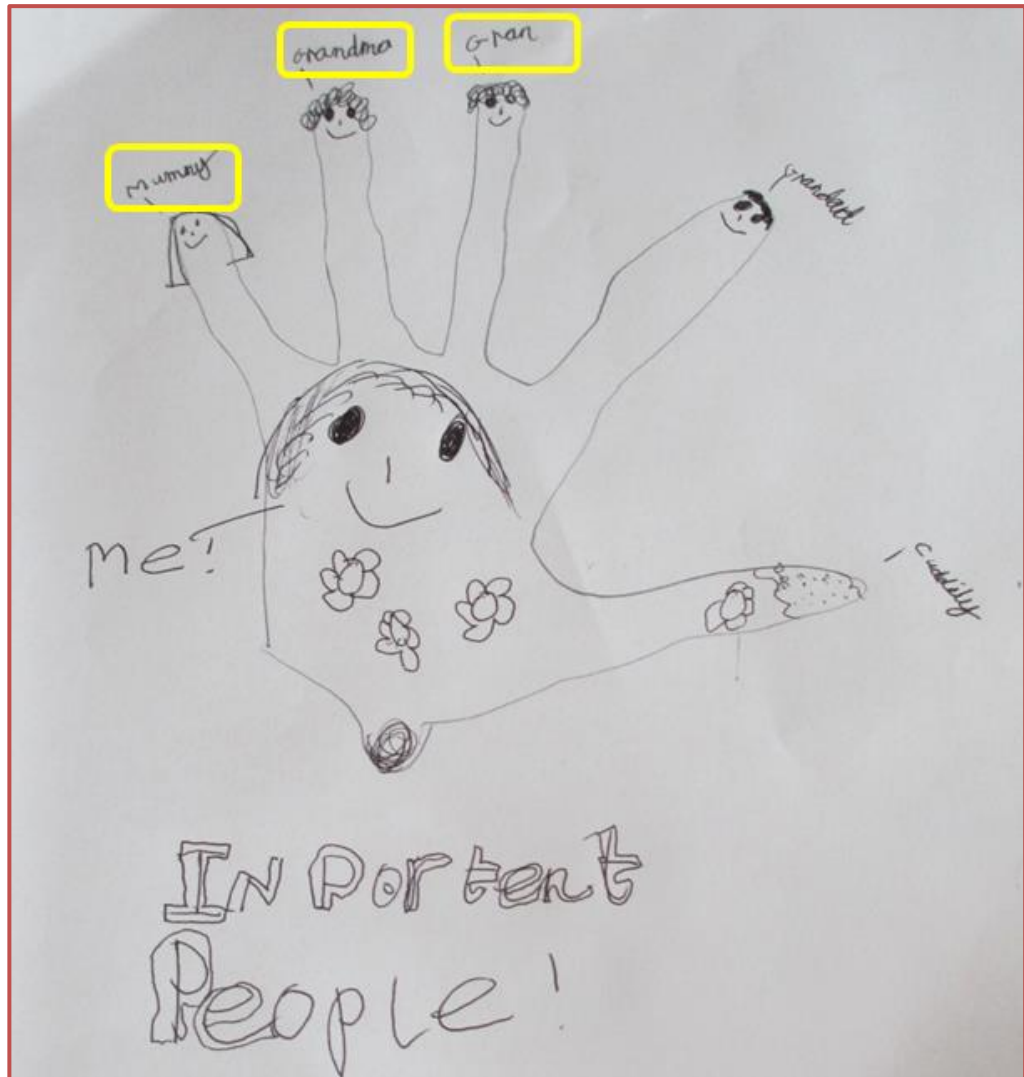
Image 32: Hand drawing of important people in Sarah's life

6.3.1   Sarah's mother's story – a synopsis

Sarah's mother's story involves a multitude of genres including tragedy, crusade and epiphany that emanates from imagery of trauma, guilt, protection and determination.

Tragedy manifests from reports of the trauma experienced due to Sarah's critical and ongoing illness. Interwoven within her story are epiphanies and crusades. Realisation of the severity of Sarah's condition and the vulnerability of her physical state is reported with imagery of navigating being a parent and doing what she perceives to be the best for her child.

Sarah's Mother: We split up when she was three months. She saw him up until about three years ago I think it would have been. It's really frustrating because she would love to see him, and I wouldn't ever stop him from seeing her.

Yet even though she knows that   he's a complete pillock, if he knocked on the door tomorrow she'd be like daddy, daddy. It's just a shame. When Sarah was in hospital I rang him to tell him, and he asked if he could come over and see her, and I said at the minute she's stable, you know, she's getting excited though when she heard my voice or my mum's voice and her blood pressure was going really high and they couldn't get it back down again, so it was almost dangerous and the nurses told us not to speak to her…So I said to him if she heard your voice she's going to get so excited, if she gets any worse I'll ring you, that's fine, and you can come over. Or if you want I'll ring you every hour and see how she is. And because I'd said that I didn't want him to come over, he told me not to bother ringing him or anything, and he's not bothered, he's not rung to see how she is or anything since. I think that's shocked Sarah a little bit. Again see I don't really like talking to her about stuff like that, because I don't want to upset her, but she asks questions and so I'm honest with her, I'd never bad mouth or anything to her because it's her dad at the end of the day. But if he did want to come and see her she'd be over the moon, but he just won't so it's his loss.'   *(Sarah's Mother)*

New adversities emerge from Sarah's ill-health that appear to place additional demands upon her mother. Subsequently, Sarah's mother's identifies trying to address Sarah's new vulnerabilities with emotional and social support as re-defining her own identity.

'Sarah's mother: It's weird. I try not to panic for Sarah, because I don't want her to then start panicking and think she's going to end up back in hospital, but I keep trying to, I mean she realises how important it is to have her purple inhaler and stuff in the morning and at night time, but yeah I just, panicking is awful… I can't say that I can't live my life properly because I can, but you know like when she is poorly, every time the phone rings at work I'm thinking oh no, is that school or is that my mum saying that Sarah's not very well or that she can't breathe or, so it is a bit, it's frightening I suppose. But I suppose it'll get better as time goes on hopefully.'   *(Sarah's mother)*

Collectively, Sarah's mother's story conforms to three life chapters that include: Sarah's deteriorating health and maternal quest for help; Sarah's critical illness and rehabilitation; and life now supporting Sarah.

6.3.2   Sarah's maternal grandma's story – a synopsis

Sarah's grandma's story interweaves imagery of loss, strengthened attachment, and anxieties. Although traumatic imagery initially features, the focus of her story relates to unknowns surrounding Sarah's health and access to services that require clarifying. During this quest, Sarah's grandma encounters epiphanies in relation to the preciousness of existence, pathways to access care, and a diagnosis for Sarah's condition. Transformation in her care-giving role results in an enhanced bond between herself and Sarah.

> *'S grandma:*   *I think she's [Sarah] quite open about it. She gets very cuddly, if I'm sitting here and she's with me she'll come and cuddle up and she'll, you know, sloppy, I love you and I'm always going to be with you and, you know, I think that's how Sarah deals with it, just by closeness sort of thing. She likes to know that you're close by, that you're not, sort of if she's upstairs, she's got a playroom upstairs here, if she's upstairs playing and I say went out into the garden or something and she came down and I'm not here, she'd get a bit panicky like where are you, you know, you have to say where do you think I've gone, I'm in the garden, just things like that. So whether that's like an after effect of what happened to her, it's just, you never know with kids, do you'*
> *(Sarah's grandma)*

Sarah's grandma's story aligns to three distinct but overlapping life chapters: Loss of family members; Sarah's deterioration and critical illness; and Sarah's rehabilitation and redefined roles.

6.3.3   Within-case analysis

Themes	Sub themes	
Mediating between the unknown and known	• Uncertainties during Sarah's critical illness	• Sarah / Mother / Grandma
	• Unknown event and missing picture	• Sarah
	• Protecting others	• Sarah
	• Mediating between attempting to fill picture whilst protecting against additional adversity	• Mother/Grandma
Worries and anxieties	• Hospitalisation and the potential of becoming critically ill	• Sarah / Mother / Grandma
	• Escalation of care and getting the right help	• Mother / Grandma
Exposure to death and dying	• Death featuring in our lives	• Sarah / Mother / Grandma
	• Exposed to the possibilities of fragility and preciousness of life	• Sarah / Grandma
	• Considering own mortality and that of others	• Sarah
Grieving for the 'healthy self' transitioning to the 'asthmatic self'	• Navigating an imposed 'asthma' identity	• Sarah / Mother / Grandma
	• Resisting change to self and social identities	• Sarah
	• Professed caring approach enforces unchanged state	• Mother / Grandma

Table 17: Case study two within-case analysis

From within-case analysis of Sarah's story (section 5.3.1, page 118) and those of her significant others feature elements of trauma, quest and communion, despite

differing in focus and themes. Collectively, four themes were identified, outlined in Table 17 (page 189).

Mediating between the unknown and known

The first theme, mediating between the unknown and known, appears in all three stories, although it differs in relation to how it manifests. For Sarah, confusion and uncertainties relate to the aftermath of her critical illness with regard to what had happened to her exposing her to a quandary. She identifies inquisition about the events and imagery relating to this experience and a desire to understand more. However, the information that her mother and grandmother disclose about her critical illness provokes anxieties and fears. She therefore, describes having to build her self- and social-identities from a void in understanding, which could explain her story being fragmented in parts.

In contrast, Sarah's mother and grandma present imagery of a known critical illness event. However, their storied experiences reveal many uncertainties in relation to Sarah's diagnosis and prognosis. There is a lack of clarity in what they perceived Sarah understood from her critical illness and how much they should disclose. Uncertainties also emanated from contemplating whether Sarah will endure residual impact from her PICU admission, and how to parent a child who is living with a chronic condition. Convergence in relation to this theme is also evident across their stories, as mediation between the quest for knowledge, disclosure of information, and concealment, feature in all accounts.

Worries and anxieties

Worries and anxieties are a dominant theme across the stories. Within Sarah's story, this theme emanates from a variety of events and imagery. Physical symptoms and outcomes of her deteriorating health are related to worries about the requirement for readmission to hospital. Worries also feature in relation to Sarah's changed social identity being constrained by her asthma diagnosis and dependence on medication. She describes her fear of being stigmatized by her peers. Furthermore, anxieties of death, her own and others' mortality, feature through recurrent imagery. Worries and anxieties also feature in Sarah's mother's and grandma's stories although the associated cause differs. Both stories pose worries in relation to the parenting style utilised since Sarah's critical illness. Focus on

'normalising' Sarah's upbringing appears to conflict with her changed being and new physical needs. They report concealing their emotions in order to protect Sarah. Particularly evident in Sarah's grandma's story were her anxieties about the accessing of care in an emergency if Sarah did deteriorate again.

Exposure to death and dying

The third theme, exposure to death and dying, manifests in all three stories and results in enhanced communion. Realisation of the mortal status of Sarah is apparent in these stories leading to enhanced familial bonding. Within Sarah's story, death and dying are associated with evocative imagery, anxieties and worries. Sarah describes contemplating death as she draws connections between events, illness and the mortality of herself and other people. Within Sarah's mother's and grandma's story, death also manifests, emanating from the uncertainty and vulnerability of Sarah's physical health. However, this is associated with epiphany or realisation of the preciousness of Sarah and the role that they have to protect her from adversity.

Grieving for the 'healthy self' but transitioning to the 'asthmatic self'

The final theme identifies the transitions experienced in relation to Sarah's health status which manifests differently in all three stories.

Sarah's story identifies dichotomous and polarised identities which appear to transform and evolve during the study period. She recognises the identity that she had prior to her critical illness and asthma diagnosis and associates this self with fun, happiness and freedom. Although she openly professes to be unchanged, her story alludes to other identities. A critical illness identity, that is a forgotten, vulnerable and an uncertain state. An indeterminate identity that is aware of her own and others' mortality, is unconfident and exposed. A chronic illness identity that is dependent on medication, vulnerable to stigma, and is an identity that Sarah would prefer to forget. Lastly, an overtly confident identity, that is outgoing and sociable. Sarah recognises conflict between these identities and uses avoidance, concealment or disregard to cope. Similarly, Sarah's mother and grandma describe mediating between different identities in order to accommodate and support Sarah's evolving healthcare and emotional needs. Sarah's mother, in particular, identifies a changed parenting role that mediates between health

surveillance and normalising. They both identify a role of protection in relation to Sarah's psychological well-being that requires oppression, concealment and de-emphasising emotions and concerns in an attempt not to dramatise. Collectively, Sarah's critical illness and asthma diagnosis is described as exposing them all to adversity and unknowns.

6.4   Case study three - James

James invited his mother, brother (15 years old), teacher and speech and language therapist (SLT) to be involved in the study. James' mother was interviewed with James' brother present in their home whilst James was at school. James' brother was interviewed alone in a local café after school one evening. James' teacher and SLT were interviewed together at James' school.

6.4.1   James' mother's story – a synopsis

James' mother tells a story of tragedy which emanates from the adversity she has encountered during her life and in relation to James' previous physical, emotional and social needs.

> *James' mother: Well we'd literally just got him sorted. He'd, you know, been diagnosed the year before with ADHD, because behaviours and that, at first support after adoption and psychologist thought maybe it was something to do with attachment issues, with things like that, but then on sort of spending more time with him and assessing him, they realised it wasn't just attachment issues, there was other stuff going on. So they got the psychiatrist and CAMHS to assess him, and she made a diagnosis of ADHD. I mean initially I was very against medication because I didn't like, didn't want to use Ritalin on him, and it took me a few months to sort of come to a decision that actually if it is going to make a difference socially, school-wise, everything-wise, then we'll use the Ritalin. We tried it and it had, and I wouldn't say it's perfect and it sorts everything, but it helps with the impulsivity. It helps with the behaviour; it helps with the hyperactivity. And he'd been on the medication for about a year and he was just settled in school, you know, the assistants that he had were able to step back a bit. He could be left with other children without hurting them or doing things that was maybe not right, and the staff could trust him and give him more and more responsibility. And he was doing well; he was doing well in his school work; he was, like I say in all aspects of life he was finding it easier.'*   *(James' mother)*

Many traumas manifests throughout the story in relation to her children's childhood and abuse, their adoption, her marriage breakdown, James' underlying

clinical conditions, his critical illness, residual disablement. She recognises the transitioning identities imposed upon her as an individual, single parent and care giver. James' mother also identifies how some of these traumas have subsided due to positive changes in their social identity since James has been critically ill.

> *'James' mother:* But with James, yeah, his concentration span, yeah, you just, it's harder now to look after him, does that make sense? A normal 12 year old would be going off playing with friends. I can't just let him go out on his own, I can't, you know, you don't know what's going to happen, but it's interesting, you know all this thing about if someone's got, not a mental health problem, but I suppose ADHD could be classed as a mental health problem, people don't understand if someone kicks off or some of his behaviours from before, but now he's got a helmet on, and he's obviously got hemiparesis, people can see there's something not quite right and it's oh poor soul, is he all right? Whereas before people wouldn't understand at all, now there's something physical -
>
> *Joseph:* And so how would people react to him..?
>
> *James' mother:* Just think he's being a naughty child, and why couldn't I be a better parent, why couldn't I control him. But I'm not saying it happened a lot, it never, it was more how he was with other children, I think, or how he didn't cope with things or he's - people wouldn't be so understanding, but now they can see something physical, people are, are you okay, do you want us to do anything, you know.'   (James' mother)

James' mother's story is focused on the past and present with a distinct lack of future script. However, elements of optimism and resilience do feature in her story despite misfortune and re-manifesting adversity. James' mother's story aligns to three life chapters: her children's childhood; James' critical illness and rehabilitation; and life now.

6.4.2   James' brother's story – a synopsis

James' brother's life story involves imagery that is traumatic, tragic and emotive. Descriptions of abuse, neglect and transition feature in his story, as shown in Image 33 (page 195).

> *James' brother:* Injury, hospital, so I was injured quite a bit and in hospital quite a bit as well, so I was piecing out some more information about it, so I went quite a few times, that's why I've put quite a few arrows. Then I was adopted...I was scalded quite a lot of times, can't remember exactly but I had quite a few bones broken, and I wasn't growing properly so I was neglected. At the time the judge wanted to come and visit but they couldn't because well they knew they did it but they couldn't get any hard evidence. So they just gave him 100 hours community service and they gave my birth mum a two year probation order. And yeah, there was

> *quite a bit going on in that few, that area'.*
>
> *(James' brother)*

Vivid imagery of James' critical illness as well as his parents' separation contributes to his trauma. However, this is situated in the background as in the narrative foreground he reports resilience and a changing identity by dynamic circumstances in his story. These relate to the difficulties he was exposed to during his education, as well as his newly defined caring role for James in which he takes pride.

> *'James' brother:* And he, me and his relationship has got stronger, because even if he hadn't have gone to hospital and stuff like that, my mum probably wouldn't have been able to babysit him now, because often I'm allowed to babysit him because my mum goes out on a Wednesday and I babysit him on a Wednesday evening for my mum, which has only started yesterday but I'm allowed to do that now.*
>
> *Joseph:* And so you say that you feel that your relationship with your brother has got stronger, in what way do you think it's got stronger?*
>
> *James' brother:* He seems to, my mum's always said I've got along with children better, like younger children, and my brother acts like a young child, and I know how to act with like loads of young children. So it's easier in some ways but it's harder in some ways.*
>
> *Joseph:* And which ways is it harder?*
>
> *James' brother:* He's, well he's got a 12 year old body so, and he still does a few 12 year old things.'*   *(James' brother)*

His story aligns into three dominant chapters: Abuse, adoption and parental separation; James' illness; and life now.
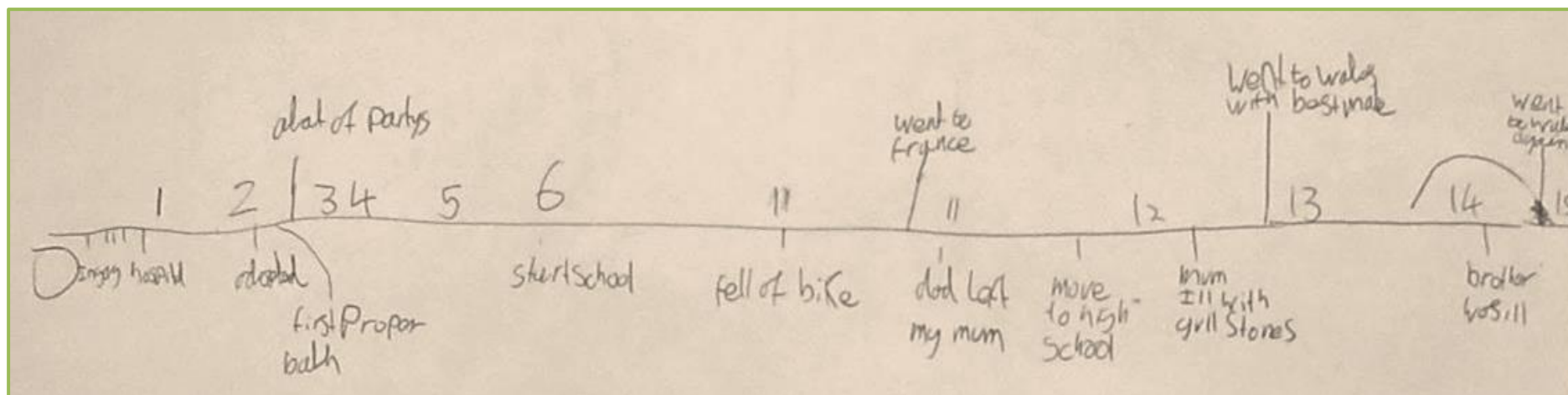
Image 33: James' brother's time line

6.4.3 James' educational story – a synopsis

James' teacher and SLT collectively provide an educational story that involves uncertainties, disruption and transformation, constructing their own characters as observers and adjuncts. James is the central character of their story and poses a dominant transformatory genre. Their story alludes to the uncertainties and issues that have manifested in relation to James's conduct.

> *'James' teacher: Post op, yeah, we have him now and so we haven't got any clear idea of how vocal or integral he was to the class that he was in prior to this. I don't know, I think there's a mixture in that group, isn't there? There are some passive members of the group, he's not the only passive member. And because of recall and the length of time it takes to get his message across, I think that could be another, you know, perhaps he recognises that that's a way of being part of the group but reducing the pressure, the anxiety about getting his message across in that group situation. I don't know, would you say?*
>
> *James' SLT: Yeah, I mean like I say, it's hard to know what he was like before and what he's like now, but obviously we can pass comment on what's happening now. And he has settled into the group, he's a lot more comfortable within the group, isn't he, and he does, like I say, he does feel, I think he feels valued within the group. There are the odd occasions like [teachers name] said when he probably needs explaining why he hasn't gone to the party, but actually there were other children in that group who didn't get invited to the party as well, so just, you know, [teachers name] helped to facilitate that.'*   *(Educational)*

They identify their roles as providing stability, as well as enablers for James to function. Their story aligns to redemptive sequence as negative imagery and events are transformed into positivity.

> *'James' teacher: So he uses a lot of the pictures as well photographs that we've got of staff that he's able to take home. That's really helpful for him to be able to explain about his day to mum, is what she's fed back to us, she's found that really useful, and we've actually enlarged it so it was better for her and for James to access those at home…there's always adults around really, so adults can help him, you know, facilitate interactions with him within the group, can't they? He is probably quiet in the group…'*
>
> *(Educational)*

Overall, their story focuses on their engagement with James in his educational social world. This appears to manifest into two main chapters: James before starting school, and James' evolving and improving self.

6.4.4   Within-case analysis

Within-case analysis of James story (section 5.4.1, page 124) and the stories of significant others illuminated that all four stories had a mixture of positive and negative tones, although they varied in chapters and dominant genres. Four main themes were identified, as outlined in Table 18.

Themes	Sub themes	
Critical illness experience	• Traumatic or unknown: disregard and avoidance of story content	• James
	• Unknown details	• Educational
	• Uncertainties and disruption	• Mother / Brother
Constrained by current being	• Existing conditions exacerbated by new complex issues	• James / Mother / Brother/ Educational
	• Quest for 'normality'	• James / Mother
	• Mismatch between perceived and actual ability/agency	• James
Changing identities within self and social worlds	• New disability redefining self, familial, educational and social identities	• James / Mother / Brother
	• Imposed caring roles, transitionary selves	• Mother / Brother
	• Social perceptions improved by physical disability to justify conduct	• Mother / Brother
	• Residual trauma	• James / Mother
Facilitators to change	• Evolving improved state	• James
	• Better dealing with young children	• Brother
	• Routine and expert support	• Mother / Educational

Table 18: Case study three within-case analysis

Critical illness experience- traumas, uncertainties and unknowns

The first theme, critical illness experience, features in all four stories. Commonalities are evident between James and the educational stories as uncertainties surrounding his critical illness feature in both. However, for James, engaging with such imagery provokes active avoidance and disregard, alluding to its potentially traumatic nature. Furthermore, traumatic imagery features in James' mother's and brother's stories. Adversities emanate from their roles as witnesses to James' deterioration and critical illness, as well as from James' uncertain prognosis.

Constrained by current being

The second theme, constrained by current being, manifests differently across the stories. In James' story it appears central, as his prior existence is where he aspires to be. Events and activities of his former life dominate his story as he constructs an able and independent existence. Similarly, nostalgic imagery is present in his mother's and brother's stories. Despite James having residual conduct, behavioural, and social problems, they report that this former 'normal' self appears more desirable than James' current existence. Subsequently, notions of grief are evident particularly in his mother's story. Conversely, the educational story constructs James' prior self as an unknown, and therefore an anti-nostalgic, forward-facing, aspirational narrative is posed.

Changing identities within self and social worlds

The third theme, changing identities within self and social worlds, manifests in all four stories and features uncertainty, burden, enhanced kinship, and raised social status. All stories allude to the multiple changes James has encountered in relation to his social circumstance, geographical location, family and parents, conduct and health status. Similar changes and challenges are reported by his sibling - however, traumatic events of neglect, abuse and separation also feature. Following critical illness, bodily disablement, cognitive and communication impairment complicate James' already chaotic status. This provokes conflicts between his desires and actual abilities, constraining his self- and social identities and exacerbating negative behaviours. Furthermore, changes to James' educational status resulted in improved behaviour and conduct.

Personal transformations also feature for James' mother and brother. In order to accommodate James' additional needs, changes to self-, social identities and family dynamics are evident. Imposed caring roles expose them to additional adversity which they address through mediation, compromise and peer support. They reflect on changes to how they and James were viewed by society prior to and post his critical illness. They recognise an improved social status due to James' visible disability (wearing a helmet) which provides an external explanation to his behaviour. Furthermore, his mother and brother believe that others have realigned their perceptions of the cause of James' 'bad behaviour'

from his mother being blamed for being a 'bad parent', to where an external cause can be located.

Facilitators to change

The final theme features in all three stories. It manifests in James' story through his recognition of small changes at home and school during the study. However, this theme is more dominant within the other three stories. Vivid descriptions are posed of the support and facilitation required to assist James' holistic rehabilitation. James' mother and brother report emotional, familial, financial and social burdens in order to meet James' dynamic needs. Despite demands on their resources, they recognise James has improved and use this to confirm and encourage their efforts. Similarly, the educational story reflects on their role as facilitators for James' evolving identity. Collectively, these stories emphasise the importance of time in James' physical, psychological and emotional recovery and identify that subtle improvement continues to be made with sustained support.

6.5   Case study four - Clare

From 14 significant others identified by Clare (shown in Image 34, page 200), she chose her mum and two sisters to participate in the study. Her mother was interviewed when Clare and her sisters were at school. Clare's younger sister (YS), aged nine years, and older sister (OS), aged 12 years, were interviewed together as requested.
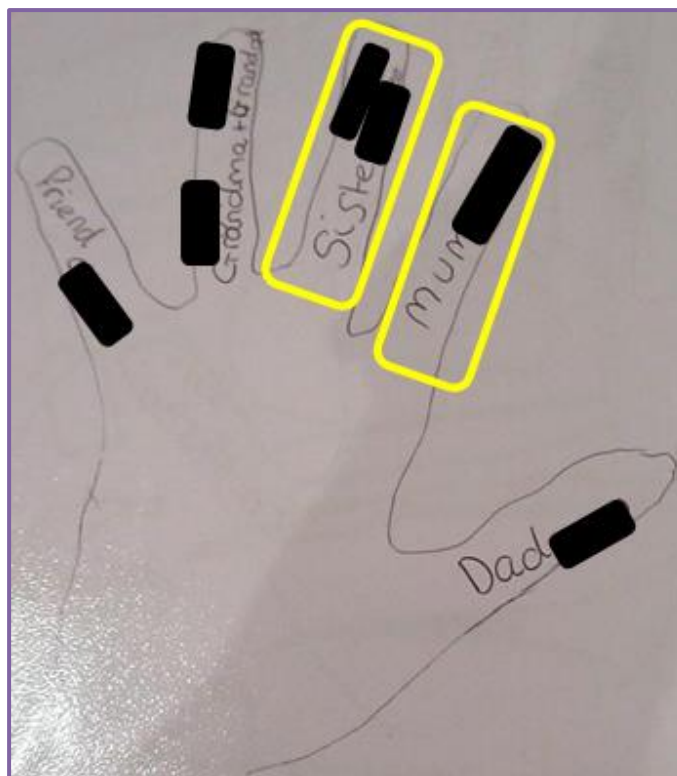
Image 34: Hand drawing identifying the significant people in Clare's life

6.5.1　Clare's mother's story – a synopsis

Clare's mother's narrative has an overall positive tone. However, her story is dynamic and includes imagery of adversities, transitions, epiphany and communion. Her story emanates from the adversity of Clare's injury and critical illness which involves panic, chaos and uncertainty.

> *Clare's mother: Oh it just seemed like a lifetime, it just seemed like, you know what I mean, you think I need somebody right now, I need a wand to get me to the hospital, I knew she was not right, and then she kind of, she'd scraped all her side. I think what she'd done, she'd had a Calippo shots from an ice cream van, you know. My kids are greedy, they like ice cream, all the kids do. But anyway she'd had this Calippo shots and I think as she's come down, she was holding this Calippo shot thing with the lollypop thing, and I think as she tripped, she must have tripped, because I said to [friend's name] did you see her, and he didn't, he just went by her on the bike and then heard the thud. So I think she's tripped and she's not been able to put her hands out because she's holding this blummin' ice cream, this lollypop so and that's how she's fallen. You just think how has she done it? How has, you know. Anyway she got this massive bump on her head and she was just, I didn't want to move her, well I couldn't, she was unconscious, she was out, and um [friend's name] was trying to get her skates off and then eventually this paramedic chap came down. You know, you just think oh thank god for that'*
> *(Clare's mother)*

This negative imagery transcends to positivity as she describes a fully physically recovered Clare who is normalised. Although recurrent adversity and trauma feature, the resilience of both Clare and her mother remains dominant.

> *Clare's mother: ...I said well can't you remember walking over the water? Because it's a real whoosh of water that you walk over, and she'd actually walked across, skated across one bit, and we're like no, no, no you're going across the wrong bit, it's this bit we've got to go around. And she's like yeah, a little bit mum, a little bit now, so it's sort of come back to her, you know, she kind of started to remember a bit, but I'm not making a fuss about that, it's a bit of a trauma, if it's gone, it's gone, you know, I don't want to bring that up. If she asks, we'll tell her, you know. But she knows, you know, there's nothing, you know, she fell over, that's it, you're poorly, you're better, let's get on with it now then, you know.'*
> *(Clare's mother)*

Clare's mother's story aligns to three life chapters: Clare's accident and a quest for appropriate help; critical care and recovery; and life now and revisiting the accident site.

6.5.2 Clare's siblings' story – a synopsis

Collectively, Clare's sisters provide a story that features tones of trauma, realisation, normalisation and transition.

As shown in their timelines (Image 35 and Image 36, page 203), much of their narrative content is enshrined in positive imagery of their everyday life. Within their descriptions they utilise empathy and reflections of thoughts and feelings of others. However, they do allude to residual trauma from Clare's injury and critical illness, and the uncertainties that emanated from that time.

> *Clare's OS:*   *I knew it was like really serious, and then she rang us later and then when they told me that they had to drill into her head I was like oh my god is she okay, I didn't have a clue what had, and then she told me not to tell [younger sibling's name] or [older cousin's name] because they would just get worried. It was horrible.'*   *(Clare's siblings)*

Their story forms three distinct life chapters that include: Life before and when Clare fell over; Clare's hospitalisation and rehabilitation; and life now, more careful but nothing changed.

6.5.3 Within-case analysis

From within-case analysis of Clare's story (section 5.5.1, page 134) and the stories of her significant others, elements of trauma, quest and communion featured that differed in focus. Three main themes were identified, as shown in Table 19.

Themes	Sub themes	
Uncertainty and disturbance	• Uncertain of the seriousness of Clare's injury • Unknown event - injury • Unknown event – critical illness • Fears and anxieties provoked • Mediating between a quest for knowledge and the protection of others	• Mother / Siblings • Clare • Clare / Siblings • Clare / Mother / Siblings • Clare / Siblings
Transitions and social isolation	• PICU to ward • Injury event • Getting definitive care • Social isolation	• Clare • Mother / siblings • Mother • Clare / siblings
'Normal' but living with the residual scars	• Back to normality • Psychosocial impact • Changed behaviours and safety dialogue	• Clare / Mother / siblings • Clare / Mother / siblings • Clare / Mother / siblings

Table 19: Case study four within-case analysis
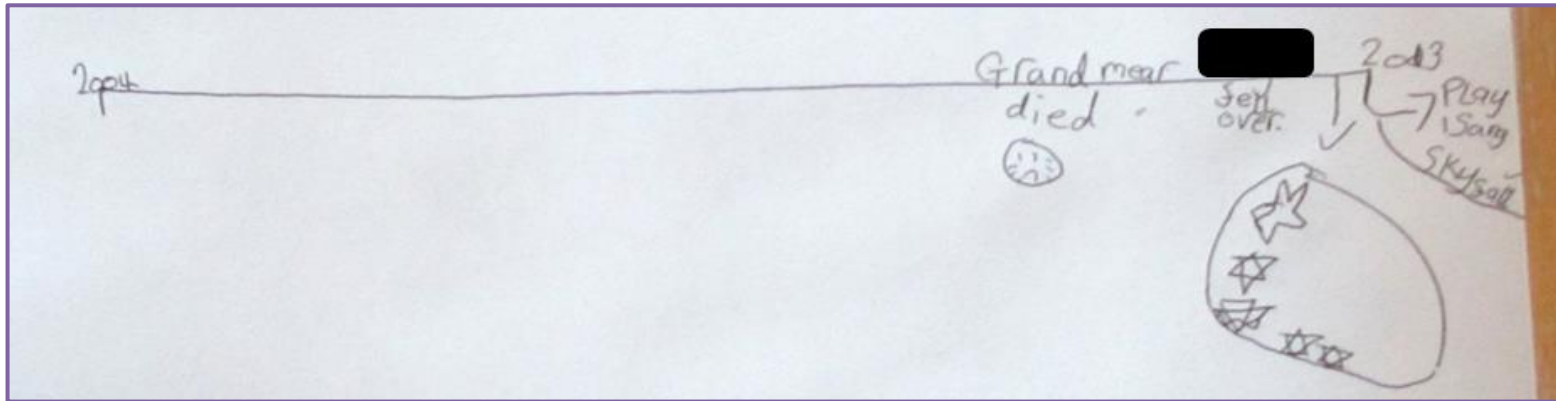
Image 35: Clare's younger sisters' timeline
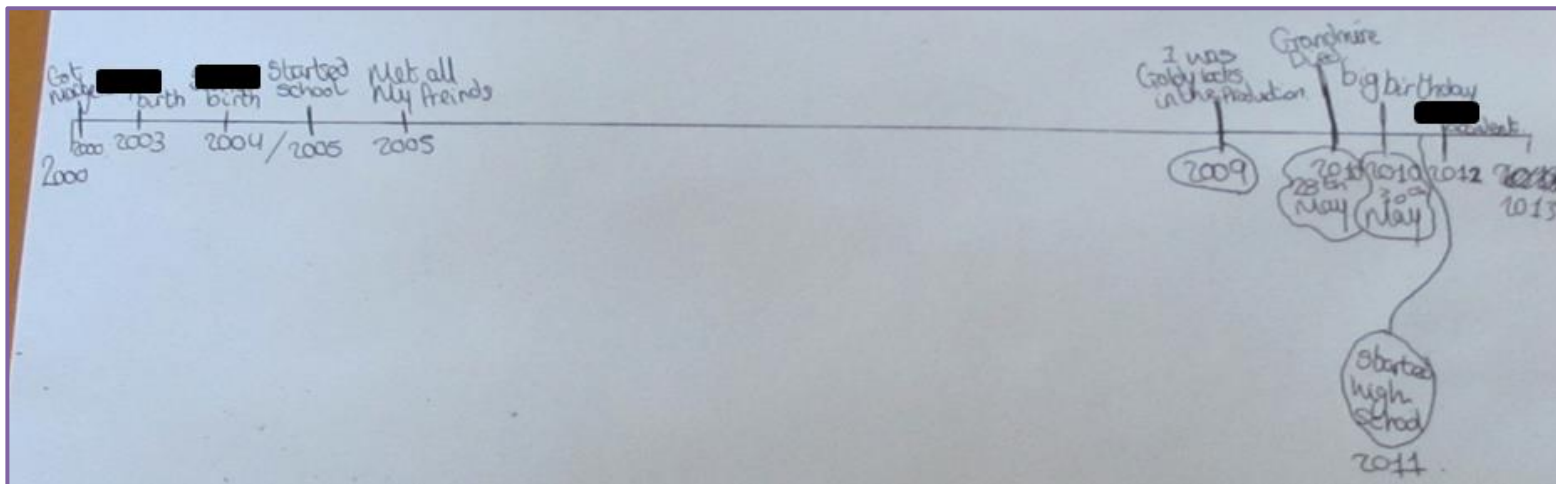
Image 36: Clare's older sisters' timeline

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Uncertainty and disturbances

The first theme features in all three stories although the events and imagery reported differ. Clare's uncertainty emanates from her confusion and amnesia following her injury and critical illness. This inability to recall this part of her life is recognised in Clare's mother's story. Clare appears to deal with this biographical disturbance by either omitting descriptions surrounding these experiences or using the stories of others to inform and build the picture. In relation to Clare's injury, her mother's story aligns to the story reported by Clare, with similar descriptions and metaphors disclosed. However, uncertainties also emanate from other aspects of Clare's mother's and siblings' stories. Unknowns in relation to Clare's condition and physical vulnerability are identified during the storying of Clare's injury event and potential outcome following critical illness. These are reported to be exacerbated through their enforced separation from Clare during her critical illness experience. Collectively, unknowns and uncertainties provoked negative emotional responses in Clare, her mother and siblings.

Transitions and social isolation

The second theme involves transitions and social isolation which manifest differently in all three stories.

Clare's story focuses on the transitions in stepping down from PICU to the ward. Although this transition is not associated with either positive or negative imagery, it is the subsequent stay on the ward that is loaded with emotive descriptions. In contrast, Clare's mother's and siblings' story provides vivid imagery about the escalation of care. Panic and chaos are reported in both accounts and allude to the urgency of the situation.

Both Clare's and her mother's stories provide negative imagery of their inpatient stay on the ward. This period of rehabilitation is portrayed by Clare as an isolating and oppressed experience. Conversely, imagery of her mother's fatigue emanates from the chaotic environment and demands placed on her by Clare. Clare's siblings similarly identify feelings of social isolation as a result of the enforced separation from Clare and their mother. This rendered them exposed to negative emotions and adversity.

All three stories report enhanced communion following Clare's discharge from hospital. However, her mother and siblings also describe mediating between protective behaviours and allowing Clare to express her own agency.

'Normal' but living with the residual scars

The final theme features in all three stories. Elements of residual emotional and psychological scars from Clare's injury event and critical illness experience feature. Lingering concerns are acknowledged through modified actions and proclaimed safety behaviours. Their stories utilise contemplation of other ill children to situate their experience and current status.

6.6   Case study five - Steve

From the outset of the study, Steve nominated his mother, his grandfather and his friend to participate. However, only his mother agreed to be interviewed. During Steve's final interview he requested that both his sisters be invited to participate. I interviewed Steve's mother in the family home, whilst Steve and his siblings were at school.   Both his younger sister (YS), aged nine years, and older sister (OS), aged 13 years, consented to participate in the study and were interviewed in the family home with Steve and his mother present.

6.6.1   Steve's mother's story – a synopsis

Steve's mother's story poses polarised imagery that aligns to a number of genres including tragedy, epiphany, communion and redemption. Negative imagery of trauma, multiple adversities and outstanding needs manifests. Steve's critical illness event is pivotal in her story in realising his physical fragility and potential mortality.

> *'Steve's mother: I think before it was a matter of okay well this is going to be a night in hospital, that's the worst it's going to be, it's an inconvenience but we deal with it. Now it's kind of like we've got to deal fast, it could be real serious, and you don't mess about it, we don't take chances… It was can I die, will I die, what happens if I stop breathing? So it was particularly at night, he was frightened to sleep in case he stopped breathing in his sleep. So for a long while I had to sit in a chair by the side of his bed until he went to sleep. That was his big, what happens if I go to sleep? But we've always kept him in the loop over what we were doing, medication, what the drill was, he knows himself what's got to happen before an ambulance is called, and he will tell you instantly. He's the first one that will say right okay I need an ambulance. And I think that,*

and he was really, I think he was, both me and his dad went and did resus training straight afterwards, I think that reassured him that both me and his dad were taking steps that we could deal with.' (Steve's mother)

Steve's mother describes the profound influence his illness has had in informing and transforming her family and social roles. This, in turn, has exposed her to additional adversity as she describes a reduction in her social and economic capital. Taking on a full-time caring role and relinquishing paid employment exposed her to financial hardship and social stigma.

Steve's mother: Up to Steve having that bad attack I was working. I am a single parent. I've been on my own for four years now. I don't have a lot of support, so it's me and the three kids, although I have got neighbours round here now. Around that time we'd had to move house in quite a hurry, there's been a lot of things happen. As that attack happened I packed in work, we'd got to the point that my boss was very good but I was getting called out practically every week to go to Steve at school. And then after that one school got even more panicky and he only had to so much as sneeze and I was called into school. And now I'm fine with that, I don't mind, and he will fake, there will be those days when he just wants out of school and he will fake it. So I'd rather it was me go up and make the call. But yes, I had to make the decision; I quit work, which was hard. It changed everything financially. It also cut me off more, I was away from a lot of my friends, I was in an area I hadn't lived in before, and all of a sudden I'm at home with a sick child.'   *(Steve's mother)*

However, she demonstrates resilience to overcome the adversity that she faces. Positive imagery emanates from descriptions of increased agency and defiance as well as enhanced family communion. Steve's mother's story aligns to three life chapters: Steve's early childhood; asthma attack, critical illness and rehabilitation; and life now.

6.6.2   Steve's siblings' story – a synopsis

Steve's older and younger sisters collectively provide a story that has a negative tone and a dominant tragic genre. Although these vary between the sisters as evident from their timelines of significant life events (Image 37 and Image 38, page 208). However, collectively they describe trauma, uncertainty, and an undulating life that has ongoing exposure to adversity.

'Joseph: And can you remember that time when he was on intensive care?

Steve's YS: Yeah. I didn't like it because I can't even last one day, and I kept on crying and crying and crying, and I didn't know what Steve, what happened to Steve because he passed out and then my Dad arrived and then we had to go. So I didn't know what happened to Steve…But then my Daddy went to intensive care and I had to stay with [father's partners name].

Joseph:	And so how do you feel thinking back about that?
Steve's YS:	It's quite upsetting. What's wrong with you?
Joseph:	And what's upsetting about it?
Steve's YS:	That I didn't know what happened to Steve, I had to stay with [father's partners name] and I really missed my Mum. And I didn't know what, how Steve was, if he was very bad, very, very bad or okay, so.

(Steve's siblings)

Enforced personal and social transitions feature in their story with parental separation and Steve's vulnerable health status directing family functioning and dynamics. Furthermore, they construct identities as monitors, protectors, and carers of Steve, particularly in relation to physical health.

'Steve's mother:	And she snaps straight out of being a typical teenage girl into right okay what have I got to do, and looking after this one when needed.
Joseph:	Do you think that's fair to say that?
Steve's OS:	Yeah.
Joseph:	And what sort of things, why do you think you've had to grow up quickly?
Steve's OS:	Because I've got to look after him. Like when I go to my Dad's, when Steve's gone into hospital or something like that, and yeah.
Steve's mother:	You're going to do the CPR training, aren't you? And they both can do a 999 call.' *(Steve's siblings)*

They allude to a transformatory existence in relation to their self and social identities in order to accommodate residual and new adversities. Steve's siblings' story aligns to three life chapters: parental separation; Steve's asthma attack and critical illness; and life now.
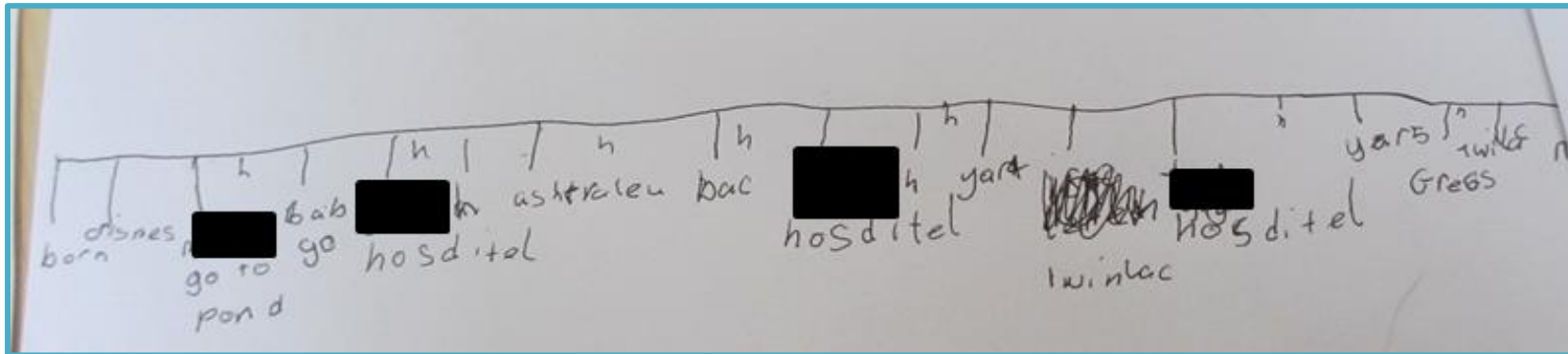
Image 37: Steve's younger sisters' timeline
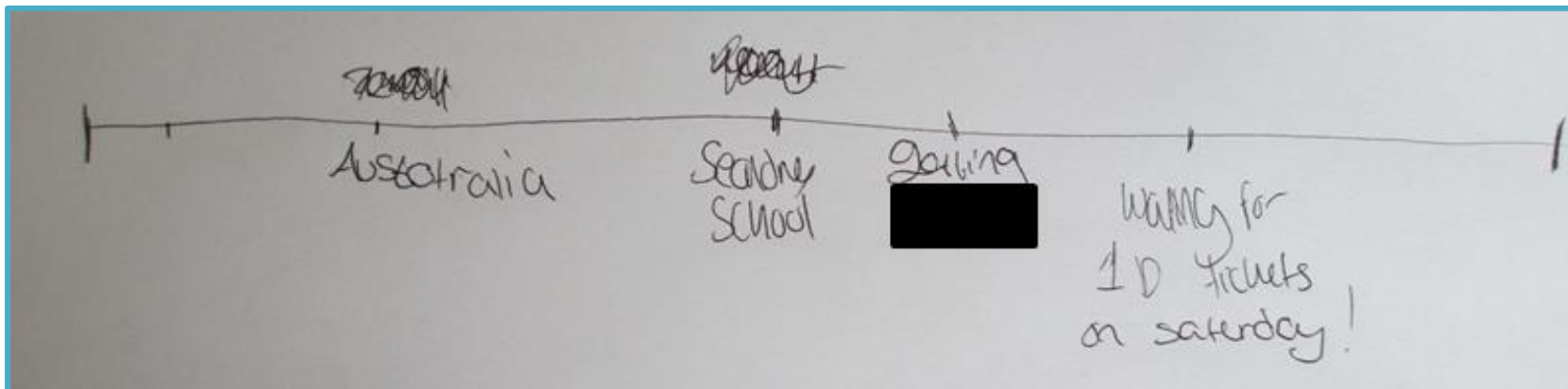
Image 38: Steve's older sisters' timeline

6.6.3 Within-case analysis

Themes	Sub themes	
Living in limbo	• Critical illness and care small strand of whole story • Realisation of Steve's vulnerable health status • Frequent access to care • Ongoing family disturbances	• Steve / Mother / Siblings • Steve / Mother / Siblings • Steve / Mother / Siblings • Mother / Siblings
Mediating hidden, normal and changed identities	• Concealed identities • Adjusted to new form • Health status and stigma (perceived) conforming identities • Enforced and dictated familial and social roles	• Steve / Siblings • Steve / Mother / Siblings • Steve / Mother • Steve / Mother / Siblings

Table 20: Case study five within-case analysis

From the within-case analysis of Steve's story (section 5.6.1, page 140) and the stories of significant others, similar life chapters and a tragic genre are evident. Two main themes emerged from the analysis, as shown in Table 20.

Living in limbo

The first theme features in all three stories and alludes to the residual and newly emerging adversities experienced. All stories report Steve's critical illness as pivotal in realising the seriousness of his condition. However, they vary in response to the residual impact of his ongoing complex health care needs. Steve appears reconciled to this residual chaos, reporting objective imagery of interventions. Steve's mother and siblings, on the other hand, report uncertainty, panic and fear in response to his vulnerable status. Furthermore, Steve's siblings describe enduring emotional detachment and social impact of the enforced separation from their mother during periods of uncertainty. Comparisons appear absent from Steve's story, while his mother and siblings allude to multiple additional adversities that occurred prior to, or following, his critical illness.

Mediating hidden, normal and changed identities

The second theme emanates from all three stories involving imagery of both unchanged and dynamic identities. Steve's and his siblings' stories disregard the idea of being changed, and instead allude to getting on with their lives by constructing a normalised identity. In contrast, Steve's mother poses normality as a quest. She recognises that, in order to achieve a state of normality for herself and her children, she is required to expend her own emotional resources. Subsequently she describes the emotional, social, and economic changes she has had to make in order to achieve this, which have in turn influenced her social capital and identity.

In addition to normality, hidden and changed identities feature within each story. Steve identifies hidden identities through omissions, as well as the content and form of his story. Omitted from his story are his emotional responses to his own critical illness and his parents' separation, as well as reference to personal health problems, such as his nocturnal enuresis. Steve overtly constructs a hidden identity and vulnerability from his peers, conforming to their norms and expectations in an attempt to avoid victimisation and retain his adolescent capital. Changed identities also feature in Steve's mother's and siblings' stories emanating from their enforced roles and responsibilities. Additional caring identities that involve protection and surveillance appear to co-exist with other selves.

6.7   Case study six - Katherine

Katherine nominated her mum, uncle and auntie to participate in the study, but only her mother consented to be involved. She was interviewed at the family home with Katherine's younger brother present.

6.7.1   Katherine's mother's story – a synopsis

Katherine's mother's story is predominantly sombre and reflective; focusing on the trauma experienced during her own life and Katherine's prolonged illness. Specifically her story focuses on a complex and chaotic plot from Katherine's delayed diagnosis and the maternal guilt experienced, through to her journey of treatment involving an undulating health status.

‘K's mother: *Oh, at first I thought, she came to me and said oh mum my gum is bleeding. Then I said because you are not brushing your teeth properly, you have to brush your teeth at least two times a day so you brush your teeth. And she came again saying mum it's bleeding. And I said okay I will book the appointment to go and see the dentist. Then I did, I booked appointment, then we go to the dentist then they say no there's nothing wrong about her teeth. Then the weekend we went out with some friends for dinner, and she was not like her because she love food, she didn't eat her food, and everyone was saying why Katherine, why Katherine? And she said no I'm not feel like eating. Then we came home, she was just complaining I feel tired. So I was saying oh if you feel tired go and have a rest...But all the time she was doing that almost for three days. Then the next weekend we go to [location 2] because my cousin was getting married. On Friday she was okay. Friday night because she loves chatting, chatting, Katherine and she was just sleeping and I was telling my brother that she keep on saying that she's tired, so just let her sleep. In the morning she didn't eat. She said I'm not feeling like eating. Then we went to the wedding. Katherine, she loved dancing, people know her dancing and singing, but that day she was just sitting down not doing anything and she asked for the car keys to go and sleep in the car. That's when I said I think she's not very well. Then after that we went home and she didn't eat as well and my brother said I think you have to make an appointment to go and see the doctor with her. I said yeah, because it was Saturday, I said I will make it on Monday if she keep on not eating and that night she said ah mum when I went to the toilet I see blood. I said maybe it's because you are having your periods. Next time when you go to the toilet can you call me? And she said okay... We sleep and in the morning she couldn't talk. That's when I'm panicking. I said what's wrong? She said I don't know. The voice was not coming out. It was like she is whispering. Then my brother called her, he say Katherine, come here, open your mouth. When she opened her mouth it was blocked with like sores, blocked on the neck. I'm panicking by then! So we come straight to the hospital and then the doctor said why did you sit with Katherine at home? I said we didn't know what was wrong and we know that she was complaining of being tired but we said we would book the appointment to see the doctor on Monday.'*

                                                                     (Katherine's Mother)

Katherine's mother provides imagery of the emotional, financial, and personal hardship she faced during this time. However, positive counter-imagery is also posed. Katherine's mother associates the problems to fate thus relinquishing agency over these events. She, therefore, refocuses her narrative to concentrate on her faith, recognising her gratitude and thanks for Katherine's survival.

‘K's mother: *the important things what happened in my life is Katherine to get better....It was important for me because I was losing it! And when they say it, that word, the match, oh it was something I keep on thinking that God must bless that person honestly because if not with that person maybe Katherine would be not here today and for the doctors they help, it was important for them to help with Katherine because I keep on thinking if she was back in Africa maybe it was a different story all in all again. Because it's so hard back home to get the bone marrow transplant and all the medication, but here it's just something which we*

Three main life chapters are identified from her story: emigration to the UK; Katherine's symptoms, diagnosis and treatment; and Katherine's improved health.

6.7.2 Within-case analysis

From within-case analysis of Katherine's story (section 5.7.1, page 148) and that of her mothers, the life chapters and narrative genres appear to align. Four analytical themes were identified, outlined in Table 21.

Themes	Sub themes	
African heritage and emigration	• Aspirations and motivations for emigration	• Katherine / Mother
	• Abandonment and anguish	• Katherine
	• Engaging the realities of the UK	• Katherine / Mother
Residual negative impact of emotional and psychological well-being	• Variation in perceived emotional and psychological impact	• Katherine / Mother
	• Traumatised by exposure to reality	• Katherine / Mother
	• Coping through evasion	• Katherine
Dynamic maternal-adolescent relationship	• Oscillating needs and desires	• Katherine
	• Draining maternal resources	• Katherine / Mother
		• Mother
	• Normal adolescent development	
Oscillating between two Worlds and many identities	• Dynamic social status	• Katherine
	• Stigma affirming transformational identities	• Katherine / Mother

Table 21: Case study six within-case analysis

Heritage and cultural transition

The first theme, heritage and cultural transition, features in both stories. This includes imagery of their African heritage and the geographical and cultural transitions experienced through emigration.

Katherine's imagery of Africa and her childhood is positive reporting happiness and fun times. She describes her upbringing as free and liberated, unconstrained by adults and the environment. Despite exposure to the mortality of loved ones early in her childhood, Katherine does not associate this time with negative imagery. She does not profess resentment or feelings of loss when disclosing her mother's emigration to the UK without her. In contrast, this aspect of Katherine's

mother's story is filled with anguish, guilt and emotional pain. Dichotomous imagery of a better life is posed against feelings of guilt about her inability to navigate the bureaucratic system in order to reunite with Katherine.

Both stories describe how their idealistic notions of the UK were tarnished by the realities of living in a different country and culture. Katherine's describes being constrained in the UK, referring to the environment and culture inhibiting her from enjoying the freedom she experienced in Africa. Similarly, Katherine's mother identifies negative imagery and emotions from being in the UK. These emanate from having to manage multiple demands of caring for a family, navigating a different culture, system and society in isolation.

Both Katherine's and her mother's stories make causal links between moving to the UK and the onset of her illness. However, for Katherine's mother, this thought evolves during her story into a counter-proposition. She contemplates the possible implications of Katherine having been in Africa when she was ill and not being able to receive health care.

Residual negative impact on emotional and psychological well-being

The second theme, residual negative impact on emotional and psychological well-being, is evident in both stories.

Katherine and her mother identify trauma and upset from a range of experiences encountered. Katherine's negative emotional imagery features throughout her diagnosis, treatment and illness, attributed to the physical pain and social isolation encountered. Physiological pain, caused by recurrent interventions, on-going treatments and therapeutic side effects, provoked emotional fatigue and anguish. Moreover, she describes how imposed isolation due to her acquired disability and treatment regime incited feelings of frustration and sadness. Similarly, Katherine's mother's describes her own stress, despair and psychological instability. She reports adversity from social isolation, exacerbated by her main care-giving role and the demands on her personal resources. Katherine's mother links her emotional and psychological well-being with Katherine's physiological status. She recognises that, when Katherine's health was particularly fragile, she was emotionally weak and near to mental breakdown.

Despite both stories posing content in relation to their future, the emotional and psychological adversity encountered during Katherine's illness remains significant. Being informed of the possibility of Katherine dying from her illness or treatment provoked significant distress. Both stories feature coping through avoiding the information-giver, the medical staff, and their information.

Dynamic maternal-adolescent relationship

The third theme comprehends the active relationship between Katherine and her mother and features significantly in both stories. Polarised imagery of enhanced communion as well as conflict is evident, which reflects the volatility of their relationship.

Katherine and her mother identify a strong maternal bond and attachment through imagery of mutual love and support. They describe a shared experience of illness, adversity and recovery which has enhanced their kinship. However, they also allude to strains placed on their relationship, provoking conflicts. Geographical separation, healthcare needs, and the demands of Katherine's brother are described as having negatively affected their relationship. This is particularly evident in Katherine's quest for recognition and assistance once she noticed the symptoms from her underlying condition. Demands on her mother's resources exposed both of them to emotional adversity. Katherine describes both her need for maternal attachment and a desire for distance from her mother due to her mother's grief. Likewise, her mother reports the burden of a multiplicity of demands being placed on her from her husband, Katherine and her son and being rendered unable to accommodate all. Both stories recognise Katherine's mother's changing role in order to accommodate Katherine's multifaceted and complex healthcare, social and psychological needs. They reveal Katherine being destructive towards their relationship by making unreasonable demands on her mother and using her to vent her anger.

Following Katherine's illness, further transformations to the maternal-adolescent relationship are described. Katherine identifies her mother as an advocate in ensuring her educational needs are met. However, she reports her mother as oppressive in preventing her from undertaking normal adolescent activities. In contrast, her mother defines her role and activities as necessarily grounding.

Oscillating between different social worlds and many identities

The final theme features in both stories and involves imagery of oscillating between different social worlds and many identities. Both stories portray Katherine with multiple identities that have been transformed through her experiences and life events. Emigration and her transition to a new society, as well as her illness, appeared to constrain her agency and impinge on her social capital, constructing a vulnerable identity. Katherine attempts to counteract this fragile state with imagery of psychological and emotional strength. She achieves this through consistently revisiting her fun and sociable identities, emphasising her forward-thinking and happy self.

Unique to Katherine's story are enforced changes to her educational identity. She describes how being put back a school year exposed her to disequilibrium amongst her peers. Due to her peers' inquisition and assumptions about her illness, Katherine was exposed to adversity that threatened her adolescent social capital. She responds through transforming her identity and adopting an externally tough and strong persona to combat this potential stigma.

6.8   Case study seven – Andrew
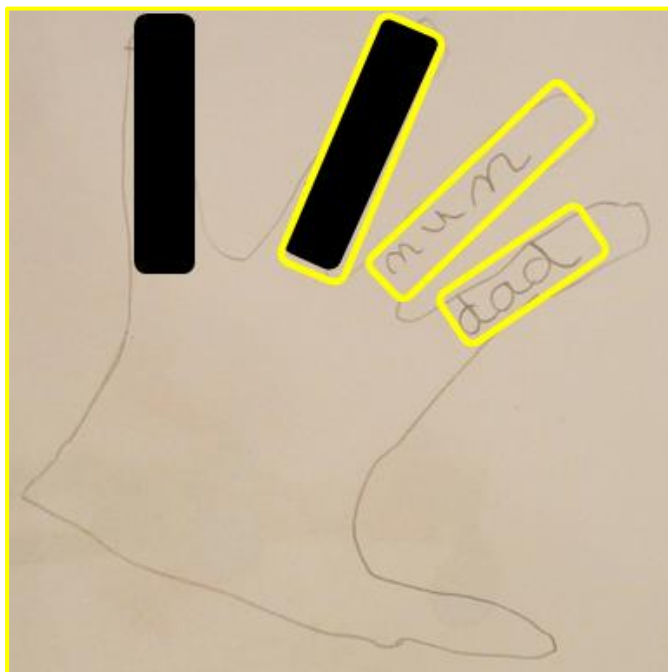
Image 39: Hand drawing identifying significant people in Andrew's life

Andrew nominated his mum, father and brother to participate in the study, as shown in

Image 39 (page 215). Due to Andrew's withdrawal from the study, only his mother and father consented to be involved. As requested, the interview was conducted at the family home with neither Andrew nor his brother present.

6.8.1   Andrew's parent's story – a synopsis

Andrew's parents' story conveys a journey of transformations and crusades that emanate from life events in relation to Andrew and his brother.

Andrew's mother:	*…From that, he was born as a strong 28-weeker, that's what they told us at two pound two, and did very well. They vented him first. He was vented for about 24 to 48 hours, and then they took him off of that and just put him on the CPAP. Then they left him for another 24 hours and they left him just in oxygen actually in the tank, the incubator, and literally he was doing very well, wasn't, they was quite surprised, his lungs and everything was, you know, really well. They only then they said right we'll start feeding him. So they started feeding and then we just noticed that what was going in didn't come out, and they wasn't really concerned at that point: there was no distension to the stomach, there was no other problems anywhere else. Literally within about a week and a half, they started saying, you know, something's going wrong here, we need to look at it. His tummy started getting distended, but generally he was okay, wasn't he? With the oxygen, you know, he was generally a well-baby, as well as could be expected, and then it, just before he was two weeks old, we had the surgeons come to us, and they'd done quite a few x-rays on his tummy and see what was going off, and then they diagnosed him with NEC.*
Andrew's father:	*Necrotising enterocolitis.*
Andrew's mother:	*Thank you. So they decided the best option for Andrew would be to have an ileostomy formed, just as a short term route to get everything out, get him growing, get him healthy, and this would be a short term thing. We didn't have a clue what stoma was, what the ileostomy would be, we hadn't got a clue; all we knew that this two pound two baby was going to be going off to theatre to have a stoma. We didn't know what it was going to look like; we hadn't images of all the intestines coming on the outside; you name it, it all went through, didn't it?*
Andrew's father:	*Yeah.*
Andrew's mother:	*They didn't give him a very big chance of survival, just because by the two weeks, everything started dropping off as they started, wanted to take him to theatre. Obviously more medication need and more oxygen started being needed. All the little things that we'd got over then started coming. So generally they took him down to theatre. It was Valentine's Day, wasn't it, 14th February, to have this ileostomy done: a tiny little button coming*

> *out of his tummy, lovely cuts across there, never seen anything before in my life like it, didn't know what to expect, and it was just literally right, let's get feeding him! And they gave him rest for a few days and all the medication and everything started kicking in, and he also needed blood which was quite scary really, knowing that your child needed blood transfusions as well to help him, and it was like oh! Red paint bags wasn't there, everywhere, and then literally after a week he started picking back up again, didn't he, and they started re-feeding him, and even though it's a week, it seems really quickly nowadays, that week seemed like months in intensive care. So every day was, there was something else. Every hour, you had another monitor bleeping at you; we had to have another medication. I think at one point, there was about 12 of –*

Andrew's father: *On the pumps yeah.*

Andrew's mother: *Pumps going in, they was all over everywhere, so generally that's how it went for a few weeks. They kept him incubated, didn't they? Which he decided to be a little bit of a [unclear] with, and kept desatting constantly, literally every 15 minutes. I used to come home to get some sleep at night and they'd be phoning up, and yeah he's just desatting, hold on a minute he's just desatting! And he did it when I was there one afternoon, and they literally just wrenched a tube out, and they found that it was blocked with blood. Hence why when it comes to saying you're profoundly deaf now Andrew, nobody knows, was it lack of oxygen when he was born, lack of oxygen due to the fact of the operation, or it was just one of those things that he was going to be profoundly deaf anyway. We don't actually know any of these answers, do we?*

Andrew's father: *No.*

Andrew's mother: *So then he got stronger and stronger, started putting on weight, and it was about four, five weeks, he came out the incubator into a warm bed, and we was allowed to hold him then. And the stoma nurse came around and said this is what you've got to do and what you're going to do, and it was very, all, you know, trying to put these tiny little bags on a tiny four pound baby was, you didn't want to do it, did you, at first, it was all left to me.'*

> (Andrew's parents)

The complexities of Andrew's healthcare needs are evident throughout his parents' story as health professionals feature as significant characters. Polarised imagery is associated with health professionals who appear to have both undermined as well as empowered parental agency during engagement.

Andrew's mother: *So I took him, this is before anything else happened to his stoma, to the [name of clinic] at the [hospital name], where we spent I think it was about three or four hours in this literally booth, and they just played all these high, intense sounds that I came out with my ears ringing at, and there was nothing. There was literally not one movement from him. The only time he actually woke up was when he was hungry, he just wasn't interested. So*

	they obviously knew that the deafness was profoundly. They wasn't allowed to tell us, so we made an appointment and we met a teacher of the deaf, so that gave us an inkling that we knew what we was dealing with, and at that —
Andrew's father:	*That was quite abrupt, that bit was, wasn't it?*
Andrew's mother:	*Yeah.*
Andrew's father:	*It wasn't a smooth —*
Andrew's mother:	*They wasn't allowed to tell you the actual diagnosis of what this scientist had got, because the research then had to go to the [name of clinic], didn't it? But they was allowed to make you an appointment at the [name of clinic] with a teacher of the deaf. So we never actually got the diagnosis until the day that we met this teacher of the deaf for the very first time and being at the [name of clinic] for the first time ever, wasn't it? And then that's when it all came together that oh yes by the way your son is profoundly deaf, this is the teacher that's going to be working with you, oh and we'll do ear moulds and everything to try and get some hearing aids in.*
Andrew's father:	*It was a Friday, we was, you did the test on the Friday so then you got three days, working days, so he'd got Saturday, Sunday, Monday, Tuesday, and then we went on the Wednesday. So you've got five days of right well he's obviously, and coming to terms with it. On our own, wasn't it, it was, that's it, there's nothing, it was more or less oh he's deaf, here's an appointment to go and see, ah right, lovely, and it was a bit daunting at that time. We'd been through everything else and then ended up with that… I don't know, it was more that he wasn't going to be, because it was so, we'd had everything else and then all of a sudden ah right, we've got this as something else to cope with.*
	(Andrew's parents)

They integrate a reflective tone within their story interweaving a complex tapestry of social and personal worlds. This includes imagery of personal hardship, adversity and anguish. They describe enforced changes to their parenting identity, social identities, personal ideology and health which result in a mixture of narrative genres that include tragedy, trauma, resilience and epiphany. However, parental resilience and endurance appear to dominate the foreground of the story.

Andrew's mother:	*— So he put all this together and basically stood up in class and said he wasn't going to deaf club. So I got called into school and then they tried to say to me your child doesn't want to go to deaf club, so I had to try and say to the school really politely that yes he is a deaf child, but when you put the cochlea implants on, he's got hearing and he knows what all these other hearing children are doing. So if you want him to go to deaf club, you've got to do it at a different time to what these hearing children are doing, because it's not fair. So somehow they came to the arrangement that deaf club then would go in afternoon just for half an hour, wasn't it now, so they could do the golden time like*

> *all the other children, because he wanted to be integrated the*
> *Same as the other children.'* (Andrew's parents)

Despite placing themselves in a complex and chaotic story, they create order and stability. Both parents construct a forward-facing, resilient story which overcomes the challenges faced.

> *'Andrew's mother:* *The only think I think's changed from Andrew being critically ill, having the seizure, is he's got stronger. And I know that sounds really silly to say, but things don't bother him. He gets upset when you talk about things like that, but he's a lot stronger minded in the sense I am going to go swimming, I am going to go and ride my bike. From having the seizure then to about the middle of August, we always got told, you know, his tummy muscles aren't very good so he might always need support riding a bike. Not Andrew, he wanted them taking off one day so we took them off, he couldn't do it, he fell off it. He grazed himself; he didn't want to do it again - normal child reaction. The next day he gets up, I'm doing it, get off, I was holding the back of the seat and thinking I'm never going to let go, I'll just keep running with him, and he told me to get off and he could do it himself.'*
> (Andrew's parents)

Due to the length and intricacy of Andrew's parents' interview, their story appears to transpose into five life chapters: pregnancy, prematurity and infancy; Andrew's deafness, life decisions, and the impact on the family; Andrew's education and social identity; deterioration, critical illness and hospitalisation; and rehabilitation.

6.8.2 Within-case analysis

From within-case analysis both Andrew's (section 5.8.1, page 157) and his parents' stories vary in genres and life chapters. Three main themes were identified, shown in Table 22 (page 220).

Themes	Sub themes	
Disengaged with critical illness experience	• Forgotten, traumatic and emotive • Unsure of relevance • Avoidance of engaging with story	• Andrew / Parents • Andrew • Andrew / Parents
Resilience despite recurrent adversity	• Forward facing outlook • Anti-sympathetic ideology	• Andrew / Parents • Andrew / Parents
Influence on agency and identity	• Influence on an ever evolving self and social identity • Facilitating autonomy and self-determination	• Parents • Andrew / Parents

Table 22: Case study seven with-case analysis

Disengaged with critical illness experience

The first theme, disengaged with critical illness experience, features in both stories although it varies between accounts. Andrew's story of his critical illness appears largely forgotten or avoided. This is confirmed by his story focusing on his present state. Subsequently, imagery of his critical illness event is minimal. However, Andrew does verbalise a blanket term 'fed-up' to describe this event. Although he is unable or unwilling to elaborate further on this, his reaction to his mother's reports infers residual trauma. His emotive response could imply that avoiding this part of his life story is a conscious choice, to minimise the psychological pain. Conversely, it could be suggested that Andrew perceives it irrelevant to discuss past events in his current life.

In contrast, Andrew's parents provide explicit reference to the emotional trauma and uncertainty surrounding his critical illness. Suppression of their parental identity and loss of control are themes that emerge from their critical care experience, describing staff as exposing Andrew to trauma through their interventions. Conversely, they also express gratitude for the care received recognising the health professionals' compassion, competence and diligence.

Despite trauma and adversity evident in both accounts, the stories consistently refer to an anti-nostalgic and self-determined approach to life. Although Andrew's parents openly engage with the imagery of his critical illness, they also describe an acceptance to disengage in order to move on with their lives.

Resilience despite recurrent adversity

The second theme features in both stories and alludes to calibrating the critical illness event within a life that is interjected with adversity.

Andrew's story, unless prompted by his mother, was forward-facing and focused on anti-nostalgic descriptions. However, by exploring Andrew's story alongside his parents, an alternative explanation can be offered. His parents' story provides imagery of Andrew's disabilities and vulnerable health status before and after he was born. Collectively, the stories allude to a rich tapestry of life events and problems that have occurred. Hence, the critical illness event is amongst a number of events that are significant, which calibrates its prominence.

Influence on agency and identity

The third theme features in both stories referring to life experiences informing their self and social identities.

Both stories construct Andrew as having strong and determined self- and social identities before and following his critical illness. Andrew's story concentrates on his current self. His identity is formed predominantly from his physical appearance, with his humour and determined character being illuminated. He demonstrates an ability to enforce his agency both in how he narrates his story and how he conducts himself in relation to events within his story.

However, Andrew's parents' story provides a relational insight into how Andrew's identity has transformed over time. They recognise the positive impact that his critical illness has had in Andrew's character and conduct. Specifically, they recognise that his expectations and subsequent behaviours have been recalibrated in line with his illness event. He is less sensitive or bothered by things now than he was before. However, they do recognise that it is difficult to attribute this change to a single event as many other changes have and continue to occur in Andrew's life.

In Andrew's parents' story they allude to the continual challenges through life events and problems. They pose an undulating journey of multiple adversities in which dynamic identities as individuals and as a family unit are constructed. These include difficult decisions and parental role re-definition exposing them to

emotional anguish. Despite adversities, they construct a unified and resilient parental identity that is able to adapt in order to meet ongoing and new physical, social, emotional and health needs.

6.9   Case study eight - Mark

Mark nominated both his parents to participate in the study. Both Mark's mother and father consented and were jointly interviewed whilst Mark and his brother were not present.

6.9.1   Mark's parents' story – a synopsis

Central to Mark's parents' story is Mark and his critical illness where the tone is predominantly traumatic. Events and subsequent problems focus on Mark's undulating physical and mental health status and render his parents with many unknowns and uncertainties.

> *Mark's mother: ... he's [Mark] had a lot to cope with. I'm sure you know about [father's name] and that happened pretty much at the same time. [Fathers name] was, let me think, [sibling's name] was three weeks old when [father's name] was diagnosed and that was in the May/June and Mark was hospitalised in the November or October. His first asthma attack was [father's name] ill, very seriously ill and then Mark was hospitalised that October and I wondered if it was related, if it was the asthma and the attack, but obviously subsequently there's been lots of them but he's had a lot to cope with as a child. And so the interesting thing for you is whether all of his anxieties are related just to the trauma or are actually a consequence of all the things that he's been through and I suspect it's all of the things.'*   *(Mark's parents)*

Despite attempts to exercise their agency to support and assist Mark to overcome the anxieties, fixations and psychological torment he experiences, their story identifies a quest for crusade with no avail.

> *'Mark's mother:*   *They took him off the respirator but then he deteriorated again, so he had a second experience and put that mask on that was like a wind, clearly, yes, clearly trying to avoid having to put him on the respirator again but he had that experience and I remember the look on his face and just trying to, mum don't let them do this, that sort of, and then go back under again and then come out again, so actually his experience was particularly -*
>
> *Mark's father:*   *Traumatic.*
>
> *Mark's mother:*   *Traumatic, yeah, I think.*
>
> *Mark's father:*   *Frightening.*

Mark's mother:	Yeah, that it wasn't just once he went through the same thing and I remember him saying, I'm going to die aren't I, I'm going to die? So he, and I know, it was explained to me at [hospital] 1 that he was given drugs and I can't remember the name of the drug now to try and prevent him having any memory of it but he seems to have, he seems to remember it. And actually they were staggered at the time that he was on, I can't remember the name of the drug again, that prevents movement, but he was on it and - hello sweetie - and they were amazed because it's meant to prevent you from moving at all. He was moving, even when he was on the respirator he was moving and they had to keep upping the dose and they couldn't believe that this little thin child could, so I don't know whether the drugs didn't quite have the impact that they were meant to have, I'm not sure but it is what it is really. It was particularly traumatic and it was meant to work, the treatment he had subsequently was meant to work, but he's been back in hospital, and he's quite an active child but he's been in and out of hospital and whenever he goes in it's that, I don't want to go or, and he's just got to go.'
	(Andrew's parents)

In engaging with others, Mark's parents' realise the magnitude of his enduring psychological manifestations. This leads to feelings of loss and despair.

'Joseph:	....Why do you think up until recently he's been able to confine them into the home, why do you think he's - do you think that's peer, embarrassment, he doesn't want to let it out to anybody else or?
Mark's father:	Yeah, I think it is.
Mark's mother:	Yeah I do.
Mark's father:	Because he did say, he said I didn't cry, dad, in front of the teacher or the class, although he said I could have done. So, that was peer pressure and not wanting to be seen to be upset.
Mark's mother:	And I think there's also an element of wanting to keep it within safe environment. He wants to be a different person; he doesn't want to be that anxious, ill child. He wants to be the athletic, because he is actually quite athletic as well, he wants to be the athletic, happy go lucky child and so I think he feels as if he can be who he is at home and is trying to divorce the two things.
	(Mark's parents)

Three life chapters emerge from Mark's parents' story that include: Mark's childhood; critical illness and transitions; and the aftermath.

6.9.2 Within-case analysis

From within-case analysis of Mark's story (section 5.9.1, page 162) and his parents, similar life chapters and narrative genres are evident. Three themes were identified, outlined in Table 23 (page 224).

Themes	Sub themes		
Residual emotional and psychological impact	• Death and dying • Fixations and worries • Living in the shadow of critical illness	• Mark • Mark • Mark / Parents	
Protection, concealment and unknown	• Different stories • Disparities in perceived cause • Parental protection vs. protecting parents: concealment discourses	• Mark / Parents • Mark / Parents • Mark / Parents	
Individual resources and agency unable to address outstanding needs	• Exercising agency to cope • Limited effect exacerbating impact • Identifying parental resources limited • Out of the system- unable to get help required	• Mark • Mark / Parents • Mark / Parents • Parents	

Table 23: Case study eight within-case analysis

Residual emotional and psychological impact

The first theme alludes to the imagery of trauma and tragedy that features in both stories. However, the perceived causes and manifestations appear to differ. Mark's story poses a traumatised self and identity that are tormented by the aftermath of his critical illness. His fixations, fears and anxieties are associated with a multiplicity of life events, experiences and problems. His physical state is overshadowed by contemplations of his metaphysical world and his spiritual, moral and ideological beliefs.

In contrast, Mark's parents suggest they are traumatised through the witnessing of Mark's vulnerable health status. Realisation of the severity of his condition and potential mortality renders them scared and uncertain. On-going uncertainty also features and is associated with Mark's psychological torment and their difficulties in trying to help.

It is evident from both stories that they differ in what they attribute the cause for Mark's enduring psychological sequalae. These differences provoke confusion and disregard between Mark and his parents, demonstrating difficulties in comprehending each other's standpoint.

Unknowns, concealment and protection

The second theme emanates from both stories although the imagery used and its focus varies. Mark's uncertainties focused on his critical illness experience and

the death of his grandparents, associated with anxieties, fears and fixations. In contrast, his parents describe uncertainties relating to a comprehensive understanding of Mark's psychological well-being. They profess unknowns in how to deal with his outstanding needs. Similarly, this features in Mark's story as he describes uncertainty about the pathway of his well-being and his future.

Mediation between concealment and protection is also apparent in both stories. Despite reporting openness with his parents, Mark describes being selective over what he discloses and conceals. He justifies concealments in order to protect his parents from worrying. Likewise, concealment features in his parents' story but as an approach to help Mark cope with evocative events. However, neither Mark nor his parents recognise the consequences of concealment on his psychological well-being.

Individual resources and agency unable to address outstanding needs

The final theme features in both stories and relates to recognising their limitations of their personal resources to address Mark's needs.

Mark portrays an evolving identity that is initially able to contain his negative thoughts and anxieties within his self and family worlds. Over time, these begin to encroach into his social world. This provokes a realisation that he is unable to cope. Mark's thoughts of death and dying provoke reflections on spirituality and the meta-physical world. This leads to a fatalistic mind-set, rendering him powerless to help himself. Similar imagery is evident in Mark's parents' story. This focused on reflecting on their inability to support and help Mark to deal with his psychological torment. This subsequently provokes reflection on their role identity as parents.

6.10   Case study nine - Ollie

Ollie nominated his mother, father and older brother (adult) to participate in the study, identified in Image 40 (page 226). All three consented and were interviewed in the family home with neither Ollie nor his younger brother present. Mother and father requested to be interviewed together and his older brother was interviewed alone.

Image 40: Hand drawing identifying the significant people in Ollie's life

6.10.1 Ollie's parents' story – a synopsis

Ollie's parents' story is complex and chaotic with imagery of multiple traumas, tragedy, grief and transformation. Uncertainty and unknowns manifest throughout their story in relation to Ollie's vulnerable health status, his critical care stay and his overall prognosis and recovery. This imagery is associated with negative emotions, particularly fear and frustration:

'Ollie's father: *I think my case my son, it was the worst two hours of my life was being stuck in London half past four in the afternoon get a phone call saying he's become ill, and to be honest because he'd been ill once before I just took it yeah okay, he'll be all right, and I'll be back tomorrow. Then literally a phone call, he's really ill, you need to come back. Then I'm on the train and [mother's name] coming out with words they don't think he's going to survive, and I'm stuck on a train trying to get back from London, just the worst two hours of my life. Because you've got two hours, just things, the most stupid things you think about. Then when I got there literally, I ran into the, I think it was the acute medical unit he was in, not intensive care…*

Ollie's mother: *And [nurses name], who looked after him from intensive care, she said that when Ollie comes round he'll be strapped to the bed or whatever, I can't remember whether he was strapped or whatever, I don't know, but he'll be in an unfamiliar thing, unfamiliar setting and whatever. She said he'll probably try and get out of the bed, he'll try and rip his tubes off, she said that's a natural reaction to what children do. And I can remember*

saying to her Ollie won't do that, and she said to me he will, but he didn't. He just opened his eyes and smiled. And that's Ollie, and I think that's what got to me. And I can remember saying to [father's name] oh he didn't deserve this, but….

…Ollie's father: He didn't deserve what happened to him, being ill.'

<div align="right">*(Ollie's parents)*</div>

Their story is dynamic and involves descriptions of health, geographical, role, and emotional transitions for both Ollie and his parents. In addition to frustration, guilt and helplessness, they identify exposure to loss of control and parental protection over Ollie:

'Ollie's Father: I think also, if you want to go back to the way lives have changed and that's, like if we go back to when he was in intensive care and this couple we made friends with, and they said it just seems to be like a roller coaster, one minute you're getting some good information and then you're going down, and it's up and down up and down. And that's how intensive care is, a bit like the programme the other night, they do a fantastic job of sensitively telling you how the situation is without building your hopes up, and they are good at that. So you are up and down, and I think this year after it, it is up and down, like I say getting sort of like not the best information from [hospital name (2)], so you go down from there, then you see [neurosurgeon name] and you come away from there thinking everything's up. And then just recently we are going down a genetics route, and they have found a problematic gene, a gene fault or mutated gene, which they're saying they don't think is related but they're not sure because it's fairly rare condition they've found. And then they've tested me and [mother's name] and this gene has come from myself to Ollie, so I don't give a monkey's about myself, you're just thinking to yourself I hope he's not going to have any more problems. So you always are going up and down a little bit, and I suppose it's changed that way a little bit but I don't know, yeah what can I say, I don't think I've got anything else.'   *(Ollie's parents)*

Ollie's parents' story identifies ongoing demands placed upon their agency. Negative emotions emanate from Ollie being stigmatised by his peers due to his physical impairment. Subsequently, this exposes them to dilemmas of parenting and mediating between protection and restriction.

His parents identify Ollie's character as significant in overcoming the multiple adversities they have faced. Despite being physically affected by his injury, Ollie is constructed as emotionally and psychologically resilient. This contrasts with imagery of his younger sibling who is described as vulnerable and withdrawn from life events.

'Ollie's mother: So [younger sibling's name] saw his brother collapse and then not see mum and dad for a week, and for some strange reason [younger sibling's name] wouldn't stay with anybody close to him. He refused to stay with

my mum and dad, he refused to stay with my sister, he ended up staying with his school teacher who is actually a friend of ours. And he was fine that week wasn't he, and then it was I think when we took him to see Ollie, Ollie couldn't talk properly, he couldn't walk and then I think that really started to affect [younger sibling's name] didn't it, and [younger sibling's name] sort of like wouldn't talk about it. And then when we tried to get all back to normal, not back to normal but carry on as best we could, [younger sibling's name] wouldn't go to school. He did, I got him there but it was a hard task. Yeah, I think it really, but he wouldn't really talk about it, he just sort of, it seemed, to anybody not knowing what had happened it would seem that [younger sibling's name] was being naughty. But I think it did really affect [younger sibling's name] didn't it?'   *(Ollie's parents)*

Four life chapters emanate from their story that include: Ollie's childhood; Ollie's accident; hospitalisation and rehabilitation; and life now.

6.10.2 Ollie's brother's story

Ollie's older brother tells a predominantly rational and optimistic story which focuses on Ollie's critical illness and the aftermath. Redemptive and communion genres are evident with elements of tragedy and epiphany. His story emanates from descriptions of surprise, urgency and chaos in relation to Ollie's accident and illness.

Ollie's Brother: *Yeah, I mean basically it all started, I came home from work, I believe it was a Friday, I'm pretty sure it was a Friday, and my dad was on the train coming back from London because he's been working there. I don't think he was intending on coming back that evening but because he'd been told by Ollie's mother that obviously something had happened, he started making his way home. And then there was like a series of phone calls basically from my view. I mean I kind of go out on a regular basis on a Friday night with my partner [girlfriend's name] parents, so I kind of, that was my plan in my head, and at first I was kind of the opinion of, you know, it'll be nothing, it's just him falling over on a playground, he's bound to just have a fever or something, nothing to worry about. And then the phone calls kept coming through kind of getting more and more severe and I could see, you know, you can just sense the tone in people's voices, that they're getting a bit panicky, and, you know, I was trying to reassure them and everything but I didn't really know. Then he ultimately rang me, I think one of the last times, saying that he'd been told by [Ollie's mother], now I can't remember the exact words, but words to the effect that it was very serious and there was a chance that he'd die, so, and he was upset by this point. So once again I reassured him, told him not to kind of panic or rush. My uncle had gone to pick him up from the train station and [location 1], and they were going to run him to the hospital. I said I'd go across, because they'd already gone across by ambulance obviously, so I said I'd go across to meet him there, and I picked up my granddad on the way across, because he'd found out, I can't remember if it was through me, I think it was kind of in a three way telephone conversation I think. He was ringing me up to see what my dad had said, my dad was ringing him to tell him, probably looking*

> *for support again I suppose from him, but I went and collected my granddad. My partner, [girlfriend's name], was with me already anyway, because we live together.'*   (Ollie's brother)

Further adverse imagery of unknowns and confusion is posed in relation to Ollie's health status and prognosis. However, he constructs a protective façade from engagement with these evocative and emotional events, problems and potential outcomes.

> *Ollie's Brother: [Hospital name] 1 a bit more fuzzy really. I know that he went up into obviously the intensive care unit. I mean [hospital name] 1 a bit more fuzzy just on the grounds that it, obviously it happened over so many nights it's hard to remember which night was which night literally. But I stayed there 'til the early hours, and then obviously the weekend was fine, and then, I say fine, Ollie was in intensive care, [Ollie's mother's name] and my dad both didn't necessarily want to leave him, they both wanted to stay. I think obviously for the duration of that weekend, it was very sketchy. I can't remember when Ollie had his surgery, how early in the process it was, but I know that it was kind of, at that point in time it was very much there was not a lot of information coming back regards whether or not he'd live or not, and so they both wanted to stay at the hospital in case the worst case scenario. So I pretty much spent most of that weekend just running errands for them, just running back and forth, going and sitting by Ollie's bed to allow them to go away, eat some food, stuff like that.*   (Ollie's brother)

Transitions emerge from his story through descriptions of the social impact of Ollie's critical illness. Perceived changes to parenting style and their negative impact on Ollie are described. However, positive imagery of Ollie's normalisation and successful rehabilitation dominates his story.   Within this story, Ollie's younger sibling is used to calibrate Ollie's recovery and status.

> *'Ollie's Brother: But like I say, normality does kick in, and slowly over the period of time my dad stopped being so worried about him I think and he started letting him get a few knocks and scrapes, and then you   get right up to now and yeah, that whole kind of cuddly period's kind of gone now, and he goes and plays his football. He does everything that a normal kid does. I mean I take him to football every now and again. I must admit when he heads the ball, you can't help but sit there thinking oh, you know, is he alright, yeah he's alright, because you know that he's had this issue and you can only think that a knock to the head can't be, well, of a choice between not being knocked to the head or being knocked to the head you'd choose the not being knocked to the head one. But you know, at the same time, I kind of think well you know, it's going to happen, can't worry about it too much… I mean my dad did tell me on a few occasions that he was cross because various children in his opinion had bullied him at school. So I don't really know, I don't really know. And the other thing, you know, it's hard - at the end of the day everyone's been through school as a child I mean what constitutes bullying and what's just seven year old kids just making observations like seven year old kids do, and you know, I'm not sure whether the situation exposed him any more or*

less to being bullied than he would do anyway. Kids will pick on kids no matter whether they've got an issue or not got an issue, so I don't know. And you know, I don't think there's anything really there now, especially to really bring him out of the crowd. I don't certainly, I mean the only time I ever see him interacting with other children is when I've taken him to football.' (Ollie's brother)

He describes how Ollie's critical illness provoked the wider family unit to consider their relationship and instigated a dialogue of enhanced communion. Two life chapters emanate from his story: Ollie's accident and hospitalisation; and life now.

6.10.3 Within-case analysis

From the within-case analysis of Ollie's story (section 5.10.1, page 172) and the stories of his significant others, common imagery featured. Four main themes were identified, as shown in Table 24 (page 230).

Themes	Sub themes	
Unknown and uncertainties	• Missing/unknown event • Need for knowledge • Conflict in professionals reports and Ollie's outcome	• Ollie / Brother • Parents / Brother • Brother
Evolving roles and identities	• 'Recovery' identity • Contemplating new needs • Demands on personal resources • Filling the void	• Ollie • Parents • Parents / Brother • Brother
Exposure to adversities	• Grateful for survival • Contemplation of Ollie's outcome: searching for justification • Realisation limitation to Ollie's ability	• Ollie • Parents • Parents
Mediating social status	• Different physical identity but same social being • Stigmatised by peers • Protecting roles vs. restriction • Uncertain of stigma but that's life	• Ollie • Parents • Parents • Brother

Table 24: Case study nine within-case analysis

Unknown and uncertainties

The first theme features in all three stories, although the imagery varies. Ollie's unknowns and uncertainties emanate from the confusion and amnesia surrounding his injury and critical illness. Although he omits descriptions relating to intensive care experience, he associates negative imagery to being physically restrained by his injury.

Ollie's parents recognise unknowns and confusion through their reporting of Ollie's injury event. Both parents describe their lack of understanding of his deterioration as he was at school. Uncertainties manifest in their quest to access appropriate care, exacerbated by the geographical separation of Ollie's parents. These continue during receipt of critical care due to Ollie's vulnerable health status.

Ollie's brother also identifies Ollie's injury and critical illness as largely unknown with limited information being conveyed through secondary sources. He subsequently associates scepticism to the accuracy of this knowledge, recognising influential factors and lenses in which it is constructed. He addresses this perceived issue by seeking information directly himself through his observations and discussions with HCP.

Both Ollie's parents and his brother identify unknowns in relation to Ollie's physical outcome in achieving his optimum recovered state. Differing stories are presented from Ollie's parents and brother who take contrasting views. Ollie's mother overtly recognises and is accepting that his physical impairment might be residual. Ollie's father and brother, on the other hand, construct determined and optimistic outlooks that focus on Ollie's further recovery.

Evolving roles and identities

The second theme features in all three stories and refers to imagery of dynamic identities. In his story, Ollie undulates between a 'recovered' and 'recovering' identity, which appears synonymous with his physical impairment and quest for normality. Ollie's parents and brother identify their evolving roles and identities imposed by Ollie's injury and disability. Their story focuses on Ollie and his younger brother, whereas Ollie's brother's story focuses on Ollie's parents. Ollie's parents signify the development of a new parental identity, dictated by the need to accommodate Ollie's new disabled form and ongoing healthcare requirements. These demands on their personal and time resource expose them to negative emotions and conflict. Ollie's brother's story involves similar imagery. However, this is ascribed to his attempts to meet Ollie's parents' outstanding needs. He constructs a role of support and assistance in order to enable Ollie's parents to function.

Exposure to adversities

The third theme relates to the exposure to adversities which features in both Ollie's and his parents' stories. Polarised imagery between these stories alludes to differing perspectives. Ollie ascribes positive imagery to exposure to adversities. Although he does allude to some negative aspects of his experience such as painful procedures, Ollie focuses his story on gratitude in surviving his critical illness.

In contrast, Ollie's parents construct a story of contemplation of his outcome, with a searching for justification for Ollie's injury and impairment. Ollie's continued limited ability provokes reflection and realisation of injustice is described. Parental grief is associated with the loss of the child they once had and the suffering they and Ollie have experienced.

Mediating social status: Protection vs. restriction

The final theme features within all three stories although it manifests differently in each. Ollie's story describes an unchanged social identity through constructing separate identities in relation to his physical and social being. He constructs a different physical identity that is impaired in relation to certain activities, such as writing. Despite recognising himself as different from others due to his disability, Ollie appears accepting of this.

Conversely, Ollie's parents pose imagery in which they perceive Ollie's new socially disabled identity as being stigmatised by his peers. They associate his impairment as 'different' or making him stand out from others due to his inability to perform in certain activities. This is perceived to have negatively impacted on his social agency with his peer group and downgraded his status. They identify how this exposes them to dilemmas in relation to their parental role and mediating between protecting and restricting Ollie.

Counter to this parental story, Ollie's brother associates doubtfulness to this proposed stigma. Instead he constructs a story undulating between optimistic and realistic imagery. He attempts to normalise these claims, ascribing the perceived stigma to normal childhood behaviours. Moreover, he identifies negative life experiences as providing Ollie with the resilience required for future life.

6.11   Chapter summary

This chapter has presented a synopsis of each of the 23 significant others' life stories. This has provided novel insights into the experiences of survival from childhood critical illness from the stories of mothers, fathers, siblings, grandparents and professionals. These stories have been analysed in the context of the case study to identify patterns, similarities and differences across stories, genres and dominant narrative themes. A multiplicity of stories is evident from 'significant others' and these converge and diverge with the stories from survivors.

Chapter Seven

Findings: Long-term psychosocial well-being of PIC survivors- insights from across the cases[33]

7.1   Introduction
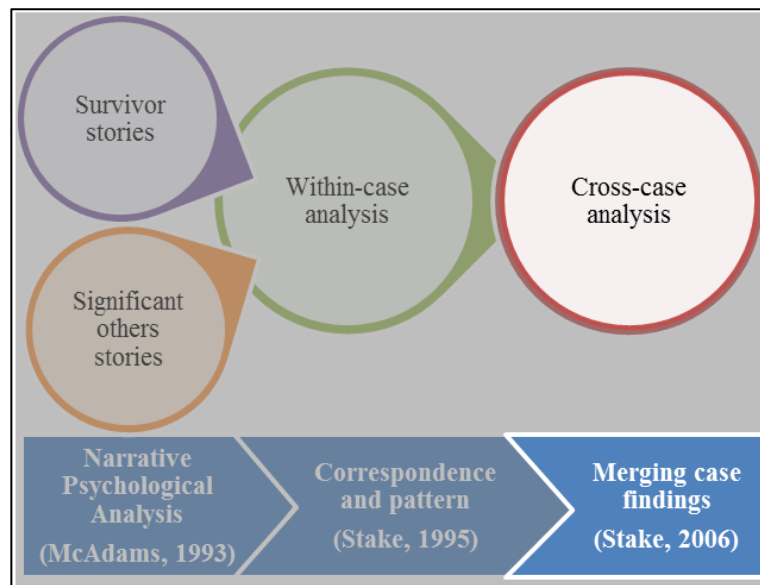
This chapter presents the findings from the cross-case analysis. Merging or aggregating findings across cases has been advocated by Stake (2006) as useful when attempting to understand the *quintain[34]*, since it allows for the degree of congruity or disparity to be explored across instances.

For this study the quintain is long-term psychosocial well-being of PIC survivors within the context of their lives. Stake (1995) proposes that interpretation and understanding of the quintain involves searching for patterns in the data across cases in order to identify important meanings. Repetition of instances gives some indication of 'interactivity' between cases and across contexts (Stake 2006).

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33 Part of this chapter has been presented as a conference presentation at the **7th World Congress on Pediatric Critical Care**, Istanbul, Turkey (5-7th May, 2014) and as a published abstract: Manning, JC., Hemingway, P. & Redsell, SA. (2014) Long-Term Psychosocial Well-Being Following Acute Life Threatening Critical Illness: Exploring Childrens' Narratives of Survival. **Pediatric Critical Care Medicine**,15 (4_suppl), 31.

34 The individual cases share a common characteristic. They may be members of a group or examples of a phenomenon. This group or category is called the quintain (Stake, 2006)

Therefore, to gain a comprehensive understanding of the quintain, whilst maintaining some context, cross-case analysis was conducted with findings from the re-told stories of survivors and the whole cases.

The first section of this chapter will present the findings from the cross-case analysis from the nine child and adolescent critical illness survivors. Analysis across the themes and genres (presented in Chapter Five) will illuminate the unity or divergence instances among survivors. The second section will outline the findings from the cross-case analysis of the nine case studies, which includes both survivors and their significant others. Dominant themes from the within-case analysis (presented in Chapter Six) will be aggregated and compared. In both of these sections, the findings from the cross-case analysis are summarised and discussed. Tables are presented to outline the unity or divergence of the categories through the occurrence (✓) or absence (box blank) of the instance within that case. Furthermore, as advocated by Stake (2006), where findings from the case feature atypically or contradict the category, 'Atyp' is written in the box.

The final section in this chapter will draw assertions from the findings of the previous two sections in relation to the quintain.

7.2 Cross-case analysis: PIC survivors

This section presents the findings of the cross-case analysis from the nine PIC survivor stories that were central to each case study. This analysis identified unity and divergence across these survivor stories in relation to the genres and themes.

7.2.1 Genres

The genre or narrative tone is defined by McAdams (2001) as the most pervasive feature of biographical stories and is, therefore, significant. The characters, events, problems, plots, and themes of the survivor stories provide insights into the genres for each story and these genre types were compared and contrasted across survivors. It is evident from Table 25 that a multitude of genres emanated from within and across the survivor stories.

Genre	Tim	Sarah	James	Claire	Steve	Katherine	Andrew	Mark	Ollie
Trauma		✓		✓	✓	✓	✓	✓	✓
Redemptive	✓	✓	✓	✓	✓	✓	✓		
Epiphany		✓		✓					✓
Crusade		✓		✓				✓	
Tragedy					✓			✓	✓
Transformatory			✓					✓	✓
Communion				✓	✓				
Optimism						✓			
Constrained			✓						
Dissociated			✓						

Table 25: Cross-case analysis (PIC survivors) of genres

This multiplicity of genres aligns to the content and form of the survivor stories, which echo the complexity and multifaceted nature of these children's lives and experiences. Trauma, redemption, epiphany, tragedy, crusade, and transformation appeared the most prevalent genres across the stories. However, redemption and trauma were the most dominant across the survivors' stories overall.

As outlined in Chapter Two, trauma has been widely associated with PIC survivors in the existing literature where critical illness experience has been constructed as iatrogenically traumatic. Despite the dominance of a traumatic tone aligning with this existing research, it is apparent that the source of this genre is not isolated to the PIC experience. Survivor accounts interweave temporal events and experiences from the past, present and future that collectively contribute to trauma manifesting.

A redemptive genre involves a plot that moves from a negative to a positive valence, bad leads to good where negative events or circumstances lead to a positive outcome (McAdams, 1999). Therefore, the initial negative state is 'redeemed' or salvaged by the good that follows it. This type of sequence was evident in all but two stories, Mark (section 5.9, page 162) and Ollie (section 5.10, page 171) and alludes to the focus on positivity and well-being despite adversity.

7.2.2   Themes

Cross-case analysis of PIC survivor stories and life chapters resulted in four dominant themes and 19 sub-themes being identified, as outlined in Table 26.

Theme	Sub-theme
1. Disrupted life story	Confusion, doubts or just missing
	Distressing memories and thoughts
	Story too distressing to revisit
	Reluctant to re-tell story
	Building my life from an unknown story
	Telling someone else's story
2. Exposed to death and dying	Contemplating the death of others
	Death-provoking fixations and worries
	Trying to make sense of own near death experience
	Surviving through avoidance
3. Dealing with different social worlds and identities	Evolving self and social identities
	Critical illness identity linked to chronic illness identity
	Protecting others through concealment
	Family supporting transitions
	Restriction and social stigma
4. Getting on with life	Focused on now and my future, not on the past
	Life challenges and future calibrated by own life story
	Determined to achieve
	Positive emotions and enhanced well-being

Table 26: Cross-case themes of survivor stories

Theme One: Disrupted life story

Disorder and disturbances featured in all survivor stories (shown in Table 27, page 238), which collectively formed the theme 'disrupted life story'. Disruptions manifested in both survivors' narrative content, such as imagery from life-events and experiences, as well as their performance.

Theme	Sub-themes	Tim	Sarah	James	Claire	Steve	Katherine	Andrew	Mark	Ollie
Disrupted life story	Building my life from an unknown story	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Confusion, doubts or just missing	✓	✓		✓	✓	✓		✓	✓
	Reluctant to re-tell story	✓	✓	✓		✓		✓		
	Distressing memories and thoughts		✓	✓			✓	✓	✓	
	Story too distressing to revisit		✓	✓		Atyp		✓	✓	
	Telling someone else's story				✓					

Table 27: The unity of theme one 'Disrupted life story' and sub-themes across the nine survivor stories

For some, such as Katherine, Mark, and James, many events appeared disrupted, contributing to disturbances in relation to their stories and biographies. For Katherine (section 5.7.1, page 148) this surrounded aspects of her childhood, specifically her father and his death. Similarly, Mark's disruptions (section 5.9.1, page 162) surrounded his childhood recollections of his father's brain tumour and his grandparents' death. Although biographical events and imagery appeared unique within survivor stories, some unity was evident. Across the majority of survivors, disturbances focused on pre-disposing deterioration, critical illness and hospitalisation experiences.

Confusion, doubts and absences was a recurrent theme in the majority of these stories, emanating from what appeared to be a near total amnesia surrounding their critical illness event. Survivors appeared to convey this disruption through omitting the event from their story or providing descriptions of absences, such as 'I don't know', or openly admitting lack of memories. For one survivor, Clare, instead of declaring the event as unknown, she conceptualises her life as being put on hold and describes the critical illness as a 'pause'. However, despite amnesia, distress surrounding their critical illness also appeared to disrupt the survivors' stories in both the content and re-telling. Distressing memories and thoughts manifested through fears and anxieties, which were associated with descriptions of

events prior, peri and post critical illness. Hallucinations, observations of other children and patients, and their transitions all contributed to disrupted imagery.

Partially formed stories and memories emanated from confusion or unknowns featured as disruption in the telling of their stories. These were particularly evident if the survivor's story did not align to that of someone else, such as a parent, which subsequently provoked uncertainties, self-doubt and further disruption. However, findings from one survivor's story, Steve (section 5.6.1, page 140), were atypical as his descriptions surrounding his critical illness were associated with imagery of bravado, largely un-emotive. Although amnesia does feature, he associates visual and linguistic imagery of calm and control to his deterioration which could be a form of coping to minimise any distress to himself or his audience.

Findings within this theme also alluded to the consequences of having a disrupted life story. Neglecting the disturbed part of their story completely, navigating around it, or just travelling from an unknown state featured across the stories and rendered some perplexed and unable to comprehend or share their experiences. Some survivors, such as Steve and James (section 5.4.1, page 124), appeared reluctant to tell their story and instead avoided engaging with the PICU event. However, for others, such as Andrew and Sarah, being exposed to the telling of their story provoked negative emotions and adversity.

Building their story and life from an unknown featured in the majority of survivor narratives and alludes to moving from a state of unknown by moving on regardless. For some survivors they situated their past, present and future imagery in their story around their critical illness, which for some meant brushing over it and, for others, neglecting it completely. However, for others, such as Ollie, it meant consciously reflecting on this deficit and disclosing the negative emotions to which it exposed them.

In contrast to the other stories, Clare (section 5.5.1, page 134) recognises the platform on which she is building her life is through telling someone else's story. She uses other people's narratives to fill in the gaps of her story. She does this with linguistic skill as, although she provides caveats to distinguish her own and others accounts, she interweaves these accounts into a comprehensive story.

Nevertheless, despite being armed with other people's stories, undertones of confusion and incomprehension are manifested.

Theme Two: Exposed to death and dying

The second theme from the survivor stories was 'exposed to death and dying'. This theme featured in findings from six of the nine narratives (as outlined in Table 28) and was particularly prominent in Sarah's (section 5.3.1, page 118), Katherine's (section 5.7.1, page 148) and Mark's (section 5.9.1, page 162) stories.

Theme	Sub-theme	Tim	Sarah	James	Claire	Steve	Katherine	Andrew	Mark	Ollie
Exposed to death and dying	Trying to make sense of own near death experience		✓		✓	✓	✓		✓	
	Surviving through avoidance		✓		✓	✓	✓		✓	
	Contemplating the death of self and others		✓				✓		✓	Atyp
	Death provoking fixations and worries		Atyp		Atyp	Atyp	✓		✓	

Table 28: The unity of theme two 'exposed to death and dying' and sub-themes across the nine survivor stories

Where contemplation of death and dying featured in a survivor's story, these appeared to be situated around the critical illness experience. It was from this event that survivors were exposed to their own mortality. Recognition of their extreme physical vulnerability emanated through their descriptions and appeared to force survivors to attempt to navigate this imagery of their own exposure to death through reflection and sense-making processes.

Contemplation of death of self and others was evident in four of the nine stories, although the theme did feature atypically in one account. Considerations of the death of others within their lives were used as platforms for Sarah and Mark to contemplate their own existence. The death of Mark's grandparents in his story (page 163) appears to enforce and exacerbate his anxieties and fixations. Obvious

grief and anger are evident from Mark's narrative content and performance and are associated with their death event and how his parents disclosed this information. Within his story, Mark uses their death to interrogate his metaphysical beliefs and subsequently his own mortality. In contrast, Sarah uses the death of her grandfather (page 120) as a platform to compare herself and her condition. From this she draws conclusions about her own mortality, for example: my grandad died from a breathing problem; I have a breathing problem; therefore I am going to die. Collectively, Mark and Sarah's contemplations of others deaths appear interwoven with their own mortality.

For other survivors contemplating the death of others was discrete from contemplating their own death. As previously identified in section 7.2.1, Katherine considers the death of her father and grandfather within her story. However, these events are separate from her own existence, and are conveyed un-emotively. Conversely, within Ollie's story (section 5.10.1, page 172), this theme features atypically as he considers the social injustices within the world and identifies the lack of resources, such as health and economic, that exposes people to death. Although the people he refers to are not related or known to him, he makes linkages between them and himself, professing gratitude for his own survival.

Contemplation of exposure to death and dying provoked negative imagery, such as fears and anxieties. These were particularly prominent in stories where the critical illness was pivotal to disease diagnosis or a chronic health condition.

For Katherine, Mark and Sarah the recall of engaging with their own mortality provoked fixations and worries. For Katherine (section 5.7.1, page 148), these worries and anxieties were constructed as an event experienced whilst she was hospitalised, but contained to the past. For Mark and Sarah, on the other hand, these were very much in their current and future scripts. Their stories provided imagery of anxieties about their death and the potential of dying in the future, although they were storied differently. For Sarah, as outlined in section (section 5.3.1, page 118) when contemplating her vicarious existence, she subtly represented her anxieties as 'worry holes' which were discrete in her story. For Mark (section 5.9.1, page 162), his descriptions of death were extremely vivid and evocative. Torment and concerns inter-relating his metaphysical world and belief

systems were presented within his reflections. Differences between how this theme manifested across survivors could have been influenced by linguistic and cognitive ability. Certainly, articulating abstract concepts of death and metaphysical worlds require narrative repertoire and thinking ability that could be governed by the age and experience of the survivor. For example, Mark disclosed during his stories that he had previously received counselling for his fixations and worries prior to his critical illness. From this therapeutic interaction he may have developed or refined his skills in discussing emotive and abstract concepts with an adult.   By contrast, it was not evident that Sarah had experienced this.

Conversely, this theme features atypically in some survivors' accounts as positive imagery is associated with their near-death event. Confessions of changes to behaviours, such as with Clare (section 5.5.1, page 134), in order to minimise any future harm as well as enhanced family and friend attachment, are reported. In the majority of stories, recognition of the emotional burden of contemplating their near-death experience or the critical illness event provoked avoidance, concealment and disengagement.

Theme Three: Dealing with different social worlds and identities

Theme	Sub-theme	Tim	Sarah	James	Claire	Steve	Katherine	Andrew	Mark	Ollie
Dealing with different social worlds and identities	Evolving self and social identities	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Family supporting transitions	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Restriction and social stigma	✓	✓			✓	✓		✓	✓
	Critical illness identity linked to chronic illness identity		✓			✓			✓	
	Protecting others through concealment		✓		✓		✓			

Table 29: The unity of theme three 'dealing with different social worlds and identities' and sub-themes across the nine survivor stories

The third theme (outlined in Table 29) evident from across the survivor stories was dealing with different social worlds and identities. This theme had high unity across survivors, evident from the dynamic imagery of changing physical, psychological, emotional and social selves reported within the stories.

For all survivors, identities were being defined and redefined during their stories. Dynamic imagery was evident through transforming physical, emotional and social selves which could be attributed to both their childhood developmental trajectory, such as growth, exposure to new life events and experiences, but also their recovering physical and physiological selves from their chronic/critical illnesses.

The stories of three survivors, in particular, depict a transformation in identity where their critical illness event was pivotal. For Sarah, Steve and Mark their critical illness event is synonymous with the realisation of the severity of their chronic illness and the inception of their dependent identity. Findings could be categorised into barriers and facilitators to these dynamic selves in navigating different social worlds and identities. These appeared to be influenced through perceived and realised limitations of their own abilities, imposed external, social and wider societal discourses.

Restrictions and social stigma were evident in six of the stories. Restrictions were associated with physical and emotional health constraints, as well as protection from health professionals, family and friends. For these survivors, restrictions were associated with constraining and impairing the evolution of their selves.

Social stigma were apparent in a number of stories (such as Sarah) but particularly in the older survivors' stories such as Mark, Katherine and Steve. However, these appeared to manifest differently between accounts. Katherine (section 5.7.1, page 148) openly disclosed stigma experienced from her peers. She used her experience to redefine herself and her social identities to enhance her social capital. In contrast, Mark (section 5.9.1, page 162), Steve (section 5.6.1, page 140) and Sarah's (section 5.3.1, page 118) self and social identities were defined by their fear of being stigmatised due to their health or psychological status. Subsequently, survivors actively concealed stories and identities from their social world in an attempt to protect themselves with varying effect.

Despite concealment being applied to protect them from stigma, this also appears to be used to protect others, invariably family members. In their stories survivors report withholding information or not broaching subjects in order to prevent

upsetting or harming others. This is evident despite an eagerness for some to either harness the knowledge or disclose it in order to get help.

Nevertheless, families were pivotal in all survivor stories to support transitions in self and social identities. They were constructed as protectors as well as advocates and enablers in order for the survivors to exercise agency, independence and perceived normality in their lives.

Theme Four: Getting on with life

The final theme (outlined in Table 30) identified across the survivor stories was on living life now featuring day-to-day life and activities.

Theme	Sub-theme	Tim	Sarah	James	Claire	Steve	Katherine	Andrew	Mark	Ollie
Getting on with life	Life challenges and future calibrated by own life story	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Focused on now and my future, not on the past	✓		Atyp	✓	✓	✓	✓		✓
	Determined to achieve	✓	✓	✓			✓		✓	
	Positive emotions and enhanced well-being	✓	✓	✓	✓		✓		Atyp	✓

Table 30: The unity of theme four 'getting on with life' and sub-themes across the nine survivor stories

The majority of survivors used an anti-nostalgic approach to conveying their story which was focused on their present and future and not their past. Even though all survivors' stories involved temporal events, focus was placed on the present and future tenses.   These dominant forward-facing perspectives mimicked the dynamic transformatory selves alluded to in theme three.

Despite stories focusing on the present and future, survivors used their life experiences to inform future aspirations and goals. For some survivors, such as Claire, this appeared to inform a changed or transformed self, viewing their lives and selves from a different perspective. However, for others such as James (section 5.4.1), and to a lesser degree Ollie (section 5.10.1), their experiences

appeared to inform what they wanted or did not want from their future. Their physically impaired selves post-PICU were not their desired transformation and they subsequently reported desires to return to their prior 'able' selves.

In addition to residual physical, emotional, psychological and social adversities being reported by survivors, positive emotions and enhanced well-being were professed by the majority of survivors. Emotional and psychological resilience was evident in the accounts of survivors, through imagery of determination and realignment of expectations being reported. This was particularly evident in survivors' aspirations and goals. However, this manifested atypically in Mark's story (section 5.9.1, page 162). Although he superficially professed a desire to be able to get on with his life and hoped that time would heal his psychological and emotional well-being, this was not the case. Through his vivid descriptions, Mark professed negative emotions and greatly impaired well-being.

7.3   Cross-case analysis: whole cases

Having discussed the quintain from across the nine PIC survivors' stories, this section will compare findings from the within-case analysis across instances.

To maintain the context of the within-case analysis, presented in Chapter Six, themes from each of the nine case studies were tabulated. Each theme was graded[35] according to their unity between the survivor and significant others within each case. From this, themes were then compared across cases to explore the unity of the themes. From the cross-case analysis of the nine case studies as a whole, four dominant themes emerged. These themes included: dynamic identities, transitioning and transforming selves; contemplation of death and evolving emotional and psychological well-being; biographical uncertainties and identity disturbances; and hope, time and professed resilience.

7.3.1   Theme One: Dynamic identities, transitioning and transforming selves

The first theme emanated from instances of actively evolving, transitioning and transforming personal, family and social selves. Evident from Table 31 (page

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[35] Unity grading included atypical (Atyp), low (L), medium (M), high (H), or a variant of any two, such as Low-Medium (L-M).

248), this theme had the highest unity within and across the nine case studies. Specifically, this theme alludes to the dynamic status of self and social identities for survivors and their significant others' post critical illness. Furthermore, interplay between the transformations of individuals within the case appears interrelated and interdependent.

Dynamic movement featured significantly in this theme as selves and identities were being constructed and re-constructed over time, across the cases. This manifested in a non-linear trajectory. Undulations between physical, psychological, social and societal fortifications appeared to define and influence agency and functioning. Chronological and biographical experiences and events, including the PIC experience, influenced current conduct and identity. However, newly emerging and evolving experiences also exposed cases to redefine themselves. In some instances, such as James' (section 6.4, page 192) and Mark's (section 6.9, page 222) case studies, this did result in conflicts in transition due to perceived constraints causing frustration. Despite this reported adversity infringing on or redefining their identities, reconciliation and acceptance of the self were evident in the majority of cases, thus indicating a level of resilience.

This theme also identifies the transformation of gendered roles and identities following the critical illness and subsequent life events. This was particularly evident in relation to care-givers and resulted in exposure to psychological and emotional flux, adversity and social stigma. For male care-givers, particularly in Tim's (section 6.2, page 180) and Ollie's (section 6.10, page 225) cases, a dominant conflict between masculinity, vulnerability and emotions exists. Desires for PIC survivors to undertake orthodox masculine activities, such as football, are posed against an inability to do so to the level required due to their impairment. Furthermore, conflicts in externalising emotions with and in front of their child due to the grief experienced exposed male carers to a position of flux and conflict. For female care-givers (mothers), having their caring role redefined appeared to impact on their personal and social identities. Greater demands on their personal resources in order to support the dynamic and complex needs of their family forced them to make somewhat difficult choices and sacrifices. This was particularly evident in James' (section 6.4, page 192), Steve's (section 6.5, page 199), Katherine's (section 6.7, page 210), Andrew's (section 6.8, page 215), and

Mark's (section 6.9, page 222) case studies, exposing mothers to impaired agency, hardship and social stigma due to imposed changes in social capital, economic and emotional status.

The survivor within the family unit features significantly within this theme as the family as well as individuals that form the collective identity are exposed to transformation and evolution. In all cases exposure to critical illness placed demands on family resources, during the critical illness experience and subsequently. It is evident from the findings that this has imposed disruption and change to family dynamics due to the changes in care-giving roles and responsibilities. Furthermore, family functioning appears to be informed by the enhanced communion emanating from the reflection about exposure to potential loss and grief. As previously identified, gendered transformation of care-giving roles, particularly parents, featured in this theme. However, care-giving responsibilities were not limited to adults - survivor siblings also identified transitions in relation to their identities. The taking on of care-giving roles, particularly within the educational environment and amongst peers, was pivotal to their identity transition.

Within-case themes	Case study								
	1-Tim	2-Sarah	3-James	4-Clare	5-Steve	6-Katherine	7-Andrew	8-Mark	9-Ollie
Evolving roles and identities	L-M		H		H	M-H	M-H	H	M
Oscillating between worlds and many identities influencing agency			H		H	M-H	H	M-H	
Constrained by current existence; longing for prior existence despite adversity manifestation		M	H					M-H	
'Normal' but living with the residual scars				H	M-H		M		
Family disruption	M		H		M-H		M	H	
Transitions and social isolation				H	M				
Hegemonic masculinity	M								M
Dynamic maternal-adolescent relationship						M-H			
Resources and agency unable to address outstanding needs			L					H	

Table 31: Cross-case analysis Theme one- Dynamic identities, transitioning and transforming selves

7.3.2 Theme Two: Biographical uncertainties and identity disturbances

The second dominant cross-case theme relates to uncertainties and disturbances to biographies and identities (shown in Table 32, page 251).

As alluded to in the previous section, across survivors this theme incorporates imagery of their amnesia of their critical illness or their inability to articulate these events. Although congruence was evident across survivors, this theme was particularly dominant in those survivors who had experienced a neurological insult, such as James (section 6.4, page 192), Clare (section 6.5, page 199), Andrew (section 6.8, page 215) and Ollie (section 6.10, page 225). It can, therefore, be proposed that the confusion and uncertainties could have been exacerbated by neurological impairment. However, across survivors, the amnesia experienced appeared to be interpreted and actioned differently. Some survivors used the stories of others to inform their biography, whereas others navigated their lives from or around these unknowns.

The juxtaposition is evident for the majority of significant other accounts which had a high unity within and across cases. This was predominantly the carers of survivors who were witnesses to the events and experiences. Their experiences do involve unknowns and uncertainties in action during the time of the critical illness event, such as their child's prognosis and trajectory of care. However, they report this event with clarity and detail. In contrast, survivor siblings as significant others align to the imagery reported by the survivors themselves. Invariably, they provide confused, disjointed accounts surrounding the critical illness event due to enduring enforced separation from the survivor and family.

Furthermore, although confusion and disturbances manifested in the biographical stories of survivors' pasts, imagery of their present and future scripts was conveyed with comprehensive fluency. In contrast, the significant others' (parents) imagery of future events was relayed with uncertainties and ambiguity.

The consequences of biographical disturbances appeared to differ across cases and survivors. Some survivors were rendered perplexed and unable to comprehend their life story. This manifested in being unable or unwilling to report their story,

thus exposing them to additional adversity. However, for other survivors, the lack of cohesion in their narrative was not problematic as they were able to mask the deficits with other imagery. Collectively, this infers divergence and subsequently uncertainties as to whether this amnesia and confusion were protective, as alluded to in the literature, or harmful. In contrast, adults in survivor lives (parents) problematised survivors' fragmented or missing pictures. A strong sense of parental need for accuracy in recall from child or adolescent survivor accounts emerged from across cases. However, despite this apparent intolerance of biographical inaccuracies, it was evident that in the majority of cases significant others were reluctant to fill in these biographical deficits. Fear and anxieties of provoking or exacerbating negative emotions existed and, therefore, biographical deficits remained.

This alludes to a broader theme that was evident across cases relating to conflicts and mediation of behaviours and actions to protect others. As outlined in the findings above, protective behaviours overtly emanated from parents to the survivor. However, subtle accounts in the survivors as well as the child significant others identify a protective reciprocity where protective behaviours and actions emanate from survivors to siblings, siblings to survivors, survivors to parents, siblings to parents, and parents to siblings. Although these protective behaviours appeared to be positive in defending survivors and significant others from perceived additional harm, they also appeared in some of the cases to disempower through lack of choice or even restraint.

Within-case themes	Case study								
	1-Tim	2-Sarah	3-James	4-Claire	5- Steve	6-Katherine	7-Andrew	8-Mark	9-Ollie
Mediating between unknown, uncertainties and biographical disturbances		H		M					H
Protecting self, protecting others: mediating between protection and restriction	M		H	M-H	M		H	M	
Mediating social status			M			M		M	M

Table 32: Cross-case analysis Theme two- Biographical uncertainties and identity disturbances

7.3.3   Theme Three: Contemplation of death and evolving emotional and psychological well-being

The third theme from the cross-case analysis encapsulates the residual and dynamic nature of the emotional and psychological well-being of the cases (shown in Table 33, page 254). This theme also appeared to have high level of unity across cases. Both negative and positive emotions were identified in this theme. However, across the cases, irrespective of survivors' chronological age, time since critical illness, reason for admission, and whether they were in receipt of healthcare prior to or since their critical illness, residual negative emotional and psychological impact was evident.

The focus of negative emotional and psychological manifestations varied amongst the cases, with worries and anxieties differing between survivors and significant others. However, some commonalities were evident. As previously identified, survivors appeared to navigate their life from uncertainties and unknowns which resulted in a disrupted story. For significant others, uncertainties also existed in relation to their personal and their family's future, as well as in how to access health, social care or parent services. Anxieties appeared also to be provoked by contemplating the survivors' future health status, trajectory of chronic illness, survivors being stigmatised by peers, and their being impeded in realising their aspirations and potential. Worries also manifested in relation to their own personal resources not being able to meet the needs of the survivor or their family. Although findings from cases focused on residual impact from the critical illness event, emerging emotional and psychological adversity due to adjustment and exposure to newly manifesting hardship was evident.

Theme two also identified divergence of how cases responded to this residual emotional and psychological adversity. Disengagement with the content and imagery of the critical illness event and experience was evident in some cases with family preferring to focus on current and future scripts. This dissociation appeared to be used as a mechanism to cope in an attempt to avoid or protect others. However, this absence of dialogue appeared, for some cases, to exacerbate the pre-existing emotion and psychological adversity.

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Contemplating vicarious death, although survived, was a finding that was dominant across a number of cases. This theme alluded to the emotional burden and torment experienced by the survivor as well as significant others within the case. Although a dialogue of death and dying was evident in some cases, for others concealment of thoughts in order to protect themselves and protect others manifested. In particular, those cases where the critical illness was pivotal or part of a chronic illness trajectory featured imagery and consideration of the survivors' mortality. Certainly, across these cases, a realisation of potential eventuality of survivor death was associated with enhanced family communion.

Within-case themes	Case study								
	1-Tim	2-Sarah	3-James	4-Claire	5- Steve	6-Katherine	7-Andrew	8-Mark	9-Ollie
Disengaged with critical illness experience due to emotional distress			M	M			M-H	H	
Worries and anxieties		M-H	H		M			H	
Critical illness experience: traumas, uncertainties and unknowns					M			H	
Residual negative impact of emotional and psychological well-being	L-M					H		H	
Positive emotions and enhanced well-being				H					
Exposure to death and dying through survival		M-H							
Enhanced communion through vicarious death		H							
Protection, concealment and unknown-focusing on death								H	

Table 33: Cross-case analysis theme three- Contemplation of death and evolving emotional and psychological well-being

7.3.4   Theme four: Hope, time and professed resilience

The final theme from the cross-case analysis 'hope, time and professed resilience' featured in all cases with medium utility (shown in Table 34, page 256). The majority of cases had a forward-facing approach to survival demonstrating defiance and resilience. An optimistic tone was posed despite the majority of cases experiencing residual and emerging adversities.

Across instances, time was used and professed as a mechanism to heal and overcome physical, psychological, emotional and social adversities. In the majority of cases, the passage of time revealed transitions and development of self and social identities. Improvements in physical selves were also apparent. However, one case was atypical of this finding. Despite Mark's case study (section 6.9, page 222) demonstrating a hope for time to overcome the emotional and extreme psychological adversities faced, the opposite was evident. This was the only case that exhibited residual and exacerbating psychological sequalae that rendered the participants in the case unable to comprehend or address the situation with the personal resources available.

Despite imagery of gratitude, hope and positive feelings emanating across the cases, torment and adversity also manifested. This was particularly prominent in cases where the critical illness experience was pivotal to disease diagnosis and those cases where survivors had chronic health conditions. Collectively, these cases were exposed to additional physical, personal and social adversity predominantly due to their vulnerable health status. Although these cases reported residual negative imagery, their identities were informed and subsequently defined by their past and elements of gratitude and enhanced family communion existed. Furthermore, some cases hoped that time might heal and provide some relief from the residual adversity experienced even though it had not done so yet within their lives.

Within-case themes	Case study								
	1-Tim	2-Sarah	3-James	4-Claire	5- Steve	6-Katherine	7-Andrew	8-Mark	9-Ollie
Resilience despite recurrent adversity	M	M	M			M	M-H		M
Living in limbo-transient critical illness event but adversity and aftermath residual.		M			H			H	
Facilitators to change; time seeing subtle improvement	M		M					Atyp	M
Exposure to adversities: gratitude vs. grief				H					M-H

Table 34: Cross-case analysis theme four - Hope, time and professed resilience

7.4   Assertions of the quintain

It is evident from across stories that numerous challenges and adversities are faced during survival which influence psychological and social worlds and subsequent well-being. This appears to emanate from disruption in relation to their life story. Confusion and uncertainties manifest that can expose survivors to additional adversity and quandary. Contemplation of their own death and dying and the mortality of others are also considered as part of the pathway of survival which can provoke additional anxieties and worries. Interplay between evolving emotional, psychological and social identities and the quest for normality by getting on with life are posed.

Interestingly, despite stories being captured at varying time points from six to 20 months post-PIC discharge, the cross-case analysis of survivors' stories does not illuminate a clear trajectory of psychosocial well-being. It is evident that survivors' stories converge at various stages during their survival that could illuminate similar psychosocial well-being. However, the exact timing or sequences of events remain undefined.

By integrating the findings from the cross-case analysis of all the cases, additional assertions are illuminated. Through the inclusion of contextually rich accounts from significant others within survivors' lives, the complexity and inter-relational nature of the long-term psychosocial well-being are further expounded. Subsequently, psychosocial well-being in the long-term appears to take a non-linear trajectory. Instead, long-term survival and well-being appear to undulate, informed by historical and current psychological and social worlds. These dynamic journeys involve ongoing and newly manifesting states of prosperity and adversity that inform how survivors project themselves within their stories and lives.

Uncertainties and disturbances appear not unique to survivors, as others within their social group construct stories of unknowns which are temporal, presided across the past, future and present. However, mediation between hidden and public stories and selves determines whether these remain hidden or unknown. This interplay appears to be used as a mechanism to cope or to protect others.
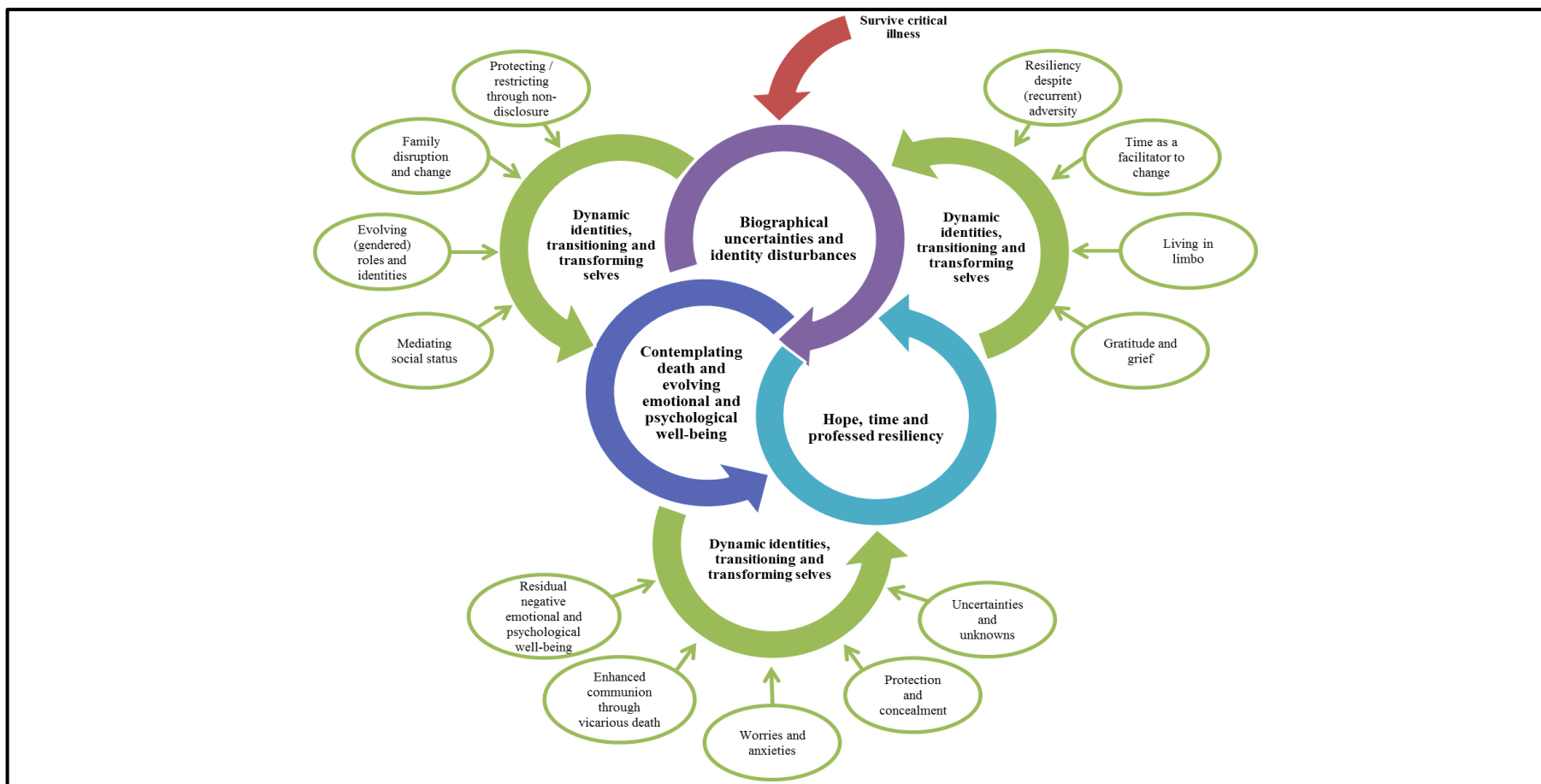
Figure 18: Schematic representation of the quintain (with examples of influential factors and themes relating to 'dynamic identities, transitioning and transforming selves' also presented).

Despite dissonance across cases, due to physical outcomes, social and family status, cross-case analysis highlighted the fundamental nature and inter-dependence of the family unit for the containment and maintenance of psychosocial well-being. However, wider social and societal influences were also illuminated. Specifically, stigma and readjustment of social identities to conform to social norms were recognised not merely for survivors but for significant others.

Despite residual and recurrent adversities, professed positivity and hope feature significantly across whole case instances. Focus on future ambitions and goals, as well as recognition and gratitude for what they have, is identified. This collectively demonstrates resilience as well as elements of transformed or transforming states in relation to psychosocial well-being as represented in Figure 18 (page 258).

7.5   Chapter summary

This chapter has presented the findings from the cross-case analysis of the nine PIC survivor stories, as well as the nine case studies as a whole.

The complexity of survivors' lives has been illuminated in this chapter with a multiplicity of imagery, themes and narrative genres evident. From the assertions drawn, PIC survivor psychosocial well-being is calibrated against past events and future aspirations. As identified in Chapters Five and Six, these are unique to each case. However, despite varying contextual, family composition and health status, converging constructions of psychosocial well-being are evident. Insights from across instances allude to the quintain as constructed from both traumatic and redemptive sequences. This imagery recognises the dynamic and inter-relational nature of long-term psychosocial well-being following critical illness, conceptualising the trajectory of survival as non-linear. Instead, long-term psychosocial well-being undulates and appears to be influenced by individual, familial, social and wider societal factors. Moreover, long-term psychosocial well-being is not uni-directional because how survivors cope and construct their personal and social selves appears consciously negotiated.

Collectively, the findings from this empirical study, presented in Chapters Four to Seven, will now be discussed and situated within the pre-existing literature in the next chapter.

Chapter Eight
Discussion and conclusion

8.1   Introduction

This chapter presents a discussion of the novel insights from this study. The major study findings will be outlined and examined in line with previous research and theory. Reflexivity and methodological considerations, including study limitations, will then be expounded.

To conclude this chapter, and the thesis as a whole, the original contribution that this study makes to the field will be outlined. Implications for future research, clinical practice and policy will be considered, and concluding personal reflections presented.

8.2   Overview of core findings

This study aimed to address a number of gaps within the existing literature (section 2.4.1, page 52), by:

  • Developing an in-depth understanding of how PIC survivors experience and construct their long-term psychosocial well-being, within the context of their lives;

  • Gaining an understanding of long-term psychosocial well-being within and across cases and contexts.

These aims have been addressed by exploring the phenomenon:

  • From the individual, through the re-told stories of nine PIC survivors (Chapter Five),

  • Within the context of bounded cases, comparing the PIC survivor stories with 23 significant others within their lives (Chapter Six),

  • As a collective, through an aggregate of instances across PIC survivors, and whole cases (Chapter Seven).

As the first UK, longitudinal, qualitative study to explore this phenomenon, the in-depth and sequential, abductive-inductive analysis has provided numerous original insights.

For the first time, this study has captured longitudinal stories from a heterogeneous group of nine child and adolescent PIC survivors, six to 20 months post-PICU discharge. Through maintaining the centrality of the inquiry on the PIC survivors, novel understanding of long-term psychosocial well-being within the context of their lives has been illuminated. Survivor stories involved complex, dynamic and inter-related identities and constructs that were inextricably linked to biographical and social worlds. Vibrant imagery of life events and contextual factors such as positivity and hope, death of others, and educational issues featured. Through longitudinal and concurrent engagement with survivors, findings have revealed previously unreported residual and newly-manifesting prosperities and adversities in this patient group.

The PIC experience featured in all survivor stories. Congruent with the variance of outcomes reported in the existing literature, the significance of the PIC event in informing long-term psychosocial well-being varied considerably between survivors. However, survivor biographies appeared significant in governing well-being as pre-existing health problems and other life events, especially traumas, appeared to dictate the significance of the critical illness.

In contrast to the reports of the negative consequences of survival that dominate the existing literature, positive descriptions, meanings and metaphors prevailed within the majority of survivor stories. Hope and quests to be normal were posed, even in traumatic accounts, which constructed resilient survivor identities. Within each story, these polarised descriptions appeared to oscillate between the fore- and back-ground, influenced by perceived relevance to the survivor at the time of telling.

From exploring within each case study, the context of PIC survivors' lives appeared complex, featuring ongoing adversities, chaos and change. Despite experiencing what could be seen as comparable context-bound events, both commonalities and differences in how these were perceived by survivors and significant others were evident.

Inclusion of stories from significant others revealed shared stories with PIC survivors that focused on future aspirations and recovery. Newly-manifesting issues and adversities that provoked contemplation and change were also told. Untold and hidden stories of past experiences and events, prognosis and the future, emanated from unknowns and uncertainties. Contemplation over which stories were shared and which were not illuminated reciprocal protection between survivors and their significant others.

Despite the individual and context-bound stories of PIC survivors being unique, the aggregation of instances highlighted converging meanings and imagery. Across contexts, novel insights into the complexity of survivor experiences and lives were illuminated. Amongst a backdrop of chaos, common themes included: disrupted lives; exposure to death and dying; mediation between different social worlds and identities; and the focus on getting on with life. Unlike the majority of existing literature that alludes to survival as a linear or uni-dimensional pathway, findings from these survivor stories identify long-term psychosocial well-being as entangled within, or set against, a multifaceted and dynamic landscape in which survivors live, experience and tell their stories. This, in turn, appears to influence how they construct and understand their well-being.

Aggregated instances across whole cases highlighted novel insights into the inter-relational nature of long-term psychosocial well-being. Despite contextual variance and composition, the pivotal nature of the family unit for the maintenance of well-being was evident. Stories of sacrifice and protection in order to meet the new and evolving needs of the PIC survivor were reported which, in some cases, exposed significant others to additional adversity. Within the contexts of their lives, survivors' constructs of psychosocial well-being appeared informed by mediating individual, biographical, familial, wider social and societal worlds. This novel finding contrasts with existing literature by highlighting the interplay between the survivor and their social worlds, as well as the dynamic and non-linear journey of survival in relation to psychosocial well-being.

It is therefore evident from these core findings that long-term psychosocial well-being following childhood critical illness is experienced and constructed: as a paradox; a state of disruption and flux; and an inter-relational and dynamic entity.

8.3 Discussion of core findings

Congruent with the orientation and approach employed in this study (outlined in Chapter Three), findings illuminate interplay between self and social worlds. In examining study findings with existing research and theory, it was apparent that they did not fit cleanly into a single field but traversed disciplines. This aligns with the literature on the origins of nursing which demonstrates how nursing as a discipline draws on both the arts and sciences to comprehend the complex and holistic nature of care and inquiry (Munhall, 2012). Therefore, diverse literature from nursing, medicine, and the social sciences has been used to contextualise and enhance understanding of the findings.

8.3.1 Long-term psychosocial well-being: a paradox

Interwoven within and between stories were contradictory and paradoxical accounts and genres. Fischer-Rosenthal (2000) acknowledges that responses to illness and disability are not necessarily stable as people's stories are filled with contradictions and inconsistencies. In relation to adult illness experience, Frank's (1995) narrative typologies (or genres) relate to quest, chaos and restitution. Although elements of these were evident in PIC survivors' stories (section 7.2.1, page 235), the same typology was not apparent throughout. Instead, findings from this study align with what Ezzy (2000) describes as 'polyphonic narratives'. Although this has been applied to the stories of adults living with a life-threatening illness (HIV/AIDS), he defines the narratives as 'overlaid, interwoven and often contradictory' (Ezzy, 2000 , p. 613.). This chaos has been attributed to the biographical processes that influence illness trajectories as they occur simultaneously and merge into each other (Corbin and Strauss, 1988). However, in relation to the stories from this study, difficulties emerged when trying to disentangle these complex and chaotic accounts. Despite these challenges, dominant enigmatic themes and stories of prosperity and adversity and hidden and public lives were evident.

Prosperous and adverse experiences and stories

Prosperous constructions of psychological and social well-being emanated within and across all stories through positivity and hope. As identified in Chapter Seven

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(page 235), positivity reigned in the foreground in virtually all accounts through redemptive genres. This could be explained by the potential therapeutic value of narratives. Telling a story is a way for people 'to gradually succeed in freeing themselves from the dominance of oppressive, problem-saturated life stories' (Neimeyer, 2000, p. 234) and replace them with more constructive ones.

However, findings demonstrate a particular focus on achievements and positive aspects of current life, with challenges and adversities in some stories being actively avoided (as evident with Steve, page 142). Hope and positivity associated with accounts of PIC survivors have been largely omitted from the existing literature. This is unsurprising as the dominant lens used to explore PIC survival has problematised or pathologised the phenomenon. However, having a strong positive outlook is recognised in the wider health literature as a mechanism for coping with stress or crisis (Walsh, 2003). Hope, or related concepts such as optimistic bias or positive illusions, have been recognised as influential in dealing with adversity (Taylor, Kemeny, Reed et al., 2000; Walsh, 2003). In relation to children's and adolescent's stories, hope has been associated with accounts of home-ventilated children (Earle, Rennick, Carnevale et al., 2006). Findings from a Canadian qualitative multiple-case study, found that, despite children encountering ongoing challenges, they remained focused on positive aspects of their life, affiliating their future with hope of 'becoming someone' (Earle et al., 2006, p. 278). Similarly, this study highlighted that children focus on the future in a manner that appears driven by the desire to resume normality.

Posed with positive imagery were adversities. For most survivors, adversities emanated from the surrounding events of their PICU hospitalisation, such as their physical deterioration and subsequent impairment. Despite certain imagery, such as drawings, being linked to the PICU environment, this was not the focus for many of the stories. In contrast to the existing literature and significant others in this research that conceptualise the PICU physical environment and interventions as iatrogenically harmful, survivors long-term stories focused on social aspects of their inpatient stay. Adversities emanated from stories of social containment, enforced isolation from parents, siblings or friends, as well as traumatic imagery of other inpatients whilst in PICU and hospital. This has been reported to manifest in the short term in studies that have collected PIC survivors' experiences up to five

days after transfer from PICU (Carnevale, 1997; Karande et al., 2005; Carnevale and Gaudreault, 2013). In these studies PIC survivors reported social discomforts from restrictions imposed upon them as well as negative emotions from recollections of the death of other children. Similar findings have been reported within the wider literature of children's longer-term experiences of hospitalisation that recognise negative responses associated with enforced separation, disruption from their routines, and segregation from their social group (Powazek, Goff, Schyving et al., 1978; Pelander and Leino-Kilpi, 2010).

Despite the diversity of PIC survivors in relation to health and socio-demographic status (outlined in Chapter Four, page 98), positivity emanated from professed gratitude and an appreciation for surviving the critical illness. In the adult ICU survivor literature, patients have been reported to experience positive psychological outcomes after a near-death experience (Cant, Cooper, Chung et al., 2012). Changes to their perspective of the world, themselves and their circumstances have been identified to occur in adult survivors due to newly-professed optimism and positivity over their life (Cant et al., 2012). This featured in the majority of stories as the critical illness appeared to provide a platform for survivors and their significant others to evaluate their lives and what was important them. For the majority, this transpired into accounts of enhanced kinship and familial bonds.

In this study life-threatening critical illness or injury exposed each survivor to potential death. However, the stories told did not align to the existing literature in relation to children that have experienced near-death experiences (NDE) (Morse, Castillo, Vanecia et al., 1986). Child reports of NDEs include out-of-physical-body sensations, viewing their own body from a vantage point, perception of darkness, travelling in a tunnel, and returning to their body (Morse et al., 1986). Furthermore, Cant et al's (2012) review of the literature identified that NDE occurs in up to 23% of critical illness patients. NDE survivors are reported to recall unusual recollections associated with a period of unconsciousness (perceived as approaching death) although they can occur in healthy individuals who may think they are in peril (Morse et al., 1986; Cant et al., 2012). However, none of these themes appeared significant in the survivor stories. Instead, it was exposure to death and dying that provoked, in some, residual and newly

manifesting worries and fears. For other survivors, this was more subtle and featured amongst a variety of narrative imagery. Contemplation of one's own mortality following critical illness, termed as 'vicarious death', has been associated with adult survivors (Zeilani, 2008, p. 135), however this has not been reported within the PIC survivor population. In this study, the critical illness event appeared pivotal to survivors in recognising the severity of their condition and the subsequent vulnerability of their own existence - thus provoking fixations, worries and associated anxieties.

For some, death of significant people within their lives featured, which heightened their awareness of dying and provoked torment and suffering. Two possible explanations could be proposed for this finding. Firstly, PIC survivors could have included imagery of death and dying within their stories due to discussions relating to their emotions. As experience of death also evoked sadness and difficult emotions, linkages could have been made. Furthermore, survivors might be able to observe similar emotions in others when someone else dies but are unable to process the emotions of others when they are ill. Contemplating one's own death and deliberating on others' mortality aligns to the literature in relation to school-aged children's recognition that death is a permanent, universal, and inevitable concept (Coombs, 2014). Curiosity relating to the physical process and exploration of what happens following death has also been associated with this age group (Coombs, 2014). Fears in relation to unknowns, loss of control, and separation from others have been identified as the main sources of anxiety, as demonstrated in Sarah's story (section 5.3.1, page 117). However, experiences and cognitive and emotional developmental levels contribute to children's engagement with death thoughts. Certainly, for adolescents, of whom Mark was one, contemplation of religious or cultural rituals was evident. As childhood and adolescence are a time of significant development relating to self and social identity, independence and peer relationships are fundamental (Leman et al., 2012). Findings suggest, such as in Mark's story (section 5.9.1, page 162), that exposure to death can challenge not only identities but also situationality within the world. Concepts of immortality are threatened, which provokes recognition of being different from peers. Although metaphysical contemplation has not been previously associated in the literature with PIC survivors, adult intensive care survivors have been reported to experience a 'spiritual awakening'

(Papathanassoglou and Patiraki, 2003). This involves transformations of the body and psyche post critical illness that provoke spiritual reflection and 'transformation of self'.

Hidden and public stories and lives

Survivor contemplation and engagement with one's own mortality appeared novel to parents (such as in Sarah's case study, page 189), indicating a paradox between hidden and public stories and lives. Hidden stories, such as those accounts that had not been previously shared, provoked declarations of disbelief as well as additional anxieties in parents when disclosed. This provides potential explanation as to why death and contemplation of one's own mortality did not feature in all survivor stories, despite being a possible outcome for all. Coombs (2014, p. 284) states, 'It has been argued that adults assume young people do not, cannot, and should not think about death'. Furthermore, the developmental ability of survivors could have been influential in their lack of disclosure to significant others, as linguistic repertoire or permission was required from other people to facilitate or scaffold the story. It might also not have been culturally acceptable to discuss death within the context of those children's lives.

Different lives and selves evolved during the data collection phase of the study, which appear also paradoxical. Constructions of overt and covert selves, hidden and public identities, as well as visible and concealed stories were told. For some survivors, their self, family, educational and wider social identities differed within their stories. It was evident that peers were significant in defining and re-constructing these identities. Issues of perceived or realised stigma from peers influenced some survivors (such as Sarah, Steve, and Mark) in masking or minimising the public face of their illness or experiences. Paradoxical identities have been identified in the stories of resilience of adolescent burns survivors (Lau and van Niekerk, 2011). Reciprocal struggles between visible and invisible selves for adolescents that experienced burns emerged from accounts of suffering and resilience. Lau and van Niekerk (2011) identify that this was facilitated and inhibited by constructions of self, and how others within their social world expected burns victims to be constructed.

Collectively it is apparent from the discussion presented in this section that many paradoxes feature in relation to experiencing and constructing long term psychosocial well-being within the context of PIC survivors lives. This polarised imagery alludes to the mediation of survivors, and those significant within their lives, of the challenges faced in developing or maintaining well-being.

8.3.2   Long-term psychosocial well-being: a state of disruption and flux

Irrespective of case or context, findings illuminated multifarious disruption and flux that appeared to emanate from within and across stories of illness and chronic ill health.

A state of disruption

Disturbances in relation to stories of illness align with what has been conceptualised by Bury (1982) as biographical disruption. He proposes that chronic illness experiences expose individuals to disruption in relation to social and practical selves (Bury, 1982). Similar to the disruption identified from the findings of the systematic review and thematic synthesis (presented in section 2.3.4, page 44), sources of confusion and uncertainty emanated from amnesia of the critical illness event. Colville et al. (2008) identify that PIC survivors can experience a mixture of factual, delusional, fragmented, and absent memories at three months post critical illness. Over one third (n=38/102) of PIC survivors had no memories of the PICU admission with 32% (n=33/102) having delusional memories which, in some cases, were highly disturbing (Colville et al., 2008). Although memory coherence did vary amongst the survivors in this study, confused and uncertain states appeared residual up to 20 months post-PIC event. Forgotten or unknown accounts that emanated from survivor stories could be partially explained by the mechanism of injury for three of the survivors, as they experienced a neurological insult, or from induced amnesia through pharmacological methods (Wagner, O'Hara and Hammond, 1997).

Irrespective of cause, amnesia appeared to impede some survivors in navigating their own biography. In this study, for some survivors (such as Clare, page 134) the lack of memory was merely disregarded which implied that amnesia was protective. However, other survivors' stories (such as Sarah, page 118) allude to the trauma that amnesia can cause. Concerns, fears and contemplation due to

confusion and unknowns were reported that, in turn, provoked contemplation of what had happened.

The navigation out of a disrupted state was negotiated by survivors through avoiding or suppressing a desire to engage with associated imagery. This aligns to what has been described in the literature as detachment or dissociation. Extensive dissociation from traumatic, unknown and damaging experiences has been observed in connection with dissociative disorders as well as in PTSD symptoms (Kenardy, Smith, Spence et al., 2007). Dissociation appears to be a plausible occurrence in this population, in line with the findings, as it can be caused by exposure to interpersonal traumas such as abuse (Simeon, Guralnik, Schmeidler et al., 2001; Van der Kolk, 2005).

For some children, such as Sarah (section 5.3, page 117), their participation in the study was the first opportunity they had had to disclose their story. This aligned with significant others' reluctance to engage in a dialogue surrounding traumatic or unknown parts of the critical care experience. Parental beliefs and actions have been reported to significantly influence the child's self-perception (Wray and Sensky, 1998) and their developing psychosocial skills. Joachim and Acorn (2000) propose that parents who directly or indirectly support their children to hide their illness or disability, or in this case their story, can lead to the child actively concealing it. However, dissociations were not isolated to survivor reports of their PIC event. Dissociation was also evident in some of the stories relating to historical events and constructions of illness, demonstrated in a preference toward forward-facing dialogues and a concentration on wellness.

Disruptions to historical and future life events, and in constructing their stories, were also evident. Prior to the PICU admission, five of the survivors had underlying medical conditions that required receipt of healthcare. Following the critical illness, the majority of survivors had ongoing health needs. Newly-acquired or realised health needs appeared to stimulate re-evaluation of how survivors functioned within their worlds and how they interacted with their selves and others. Charmaz (1983) acknowledges that chronic illness exposes individuals to loss of self through social isolation, altered expectations and identity. For most of the survivors, the critical illness was pivotal to realising the severity of an

existing health condition or start of a chronic condition, predominantly disability. Realisation through diagnosis of an existing condition transpired through survivors' accounts, evident in Steve's (section 5.6, page 140) and Mark's (section 5.9, page 162) stories. However, survivor responses to this epiphany varied, with some survivors, such as Steve, navigating this new health identity with confidence and nonchalance. This could be explained by what Habermas and Köber (2014) identify as biographical reasoning, where life stories buffer the effect of disruption on the sense of self-continuity. To do this, an individual draws linkages between parts of their past, present and future lives (Habermas, 2011). In relation to Steve's story, his severe and complex health problems, as well as potentially traumatic social events, could provide him with a platform on which to reason and situate his critical illness event. However, for others, such as Mark, adversity emanated from this realisation that was not buffered through reasoning. Instead, contemplation provoked uncertainties and traumatic imagery of vicarious death.

A state of flux

Survivors navigating and mediating between disturbances alluded to a state of flux. Former lives appeared pivotal to informing future selves. However, quests for normality provoked quandary as aspirations to return to former selves whilst also having a forward-facing existence conflicted. For some survivors, this resulted in conflicts of roles, identities, and status, which provoked transformations in self and social identities. Ashbring's (2001) study exploring women who experienced chronic fatigue syndrome and fibromyalgia, outlined that new concepts of identity were created following illness diagnosis. Ashbring identifies that this transcends self and social worlds and involves periods of evaluation and re-evaluation causing disruption, loss and gains (Asbring, 2001). Some survivors reported the consequences of having a residual chronic health need on their social status and peer relationships. Similar to findings reported by Kirk (2008) in relation to transitions experienced by young people with complex health needs, some survivors were forced to conform to different identities (such as a disabled identity) and negotiate new worlds (such as a different peer group) . Disruptions, therefore, emanated from a requirement to adjust and realign in relation to their newly-expected self and social identities.

Disruption and flux from navigating stigma

For some survivors, disruption emanated from perceived or realised stigma from peers in relation to having a chronic health condition. Findings identified that stigma conformed and re-formed survivors' selves in relation to expected social norms and roles. Social stigma and suffering have been reported by Carnevale (2007) in his study with children requiring long-term ventilation at home. He applies Goffman's (1963) Theory of Stigma, developed from published works on the experiences of people with disabilities, impairment, and mental illness. Goffman (1963) asserts that society categorises people on the basis of normative expectations, thereby segregating the 'normal' from the 'deviant'. Based on this theory, Carnevale (2007) proposes that children living with disability and illness, and their families, experience stigma through disputes, isolation and distress. However, he notes that children navigated this stigma through the use of 'passing strategies' in attempts to appear normal to peers (Carnevale, 2007). Findings in this study identify that passing strategies featured through forward-facing stories and lives that avoided the imagery of adversity. For example, in section 5.3, Sarah describes concealing taking her medication for asthma in front of her peers to appear normal. This social concealment provoked disruption and mediation between public and family selves. Even in survivors where passing strategies were not an option due to the residual effects of their critical illness (such as James, page 124, having to wear a helmet), mediation was evident.

Similar to the paradoxes (outlined in section 8.3.1, page 264), Little, Jordens, Paul et al. (1998) refer to 'fluctuation' between disturbances and resolution. Frank (1995) alludes to an 'oscillating trajectory' whereby individuals move between states of 'wellness' and 'illness'. He uses the metaphor of 'illness as travel' where individuals with chronic illness have 'dual citizenship' of wellness and sickness (Frank, 1995, p.9). Although for many of the survivors this dual citizenship in relation to their health status was evident, more pronounced was the requirement to keep an eye on the past as well as the future, living in a dualistic world that imposed flux and, in some cases, dilemmas. This was more prominent in some cases than others, such as James' case (page 197) where multiple diagnoses and a range of professed emotional, social and behavioural needs manifested. This resulted in flux as he yearned for his physical self prior to stroke, but his current,

more socially-accepted self was also desired. This finding does not align with biographical disruption as Bury (1982) defines it, but appears more congruent with what Bray, Kirk and Callery (2014) describe as 'disrupted expectations'. Bray et al. (2014) explored the experiences of children living with a stoma through their biographies. They describe how when complications occurred, misalignment in both children's and their parents' expectations and their outcome following surgery intruded on their daily lives and functioning. Subsequently their health needs featured more largely than was expected, thus leading to disrupted expectations and aspirations (Bray et al., 2014). In this study, divergence between survivor and parental narratives was evident as aspirations to normalise radiated from parental, particularly fathers', accounts. This was particularly evident in Tim's (section 6.2, page 180) and Ollie's (section 6.10, page 225) cases. For some, such as James, this posed a status of living in limbo, where survival and the recovery post critical illness was not perceived as complete, as desires for his prior, 'normal' self persisted.

However, amongst these disruptions (whether biographical or aspirational) and adversities, the focus of survivor's and significant others' accounts remained on normality and the future (such as in Andrews case, section 6.8, page 215). Similar to notions of hope evident in the stories (discussed in section 8.3.1, page 264), this demonstrated a resiliency in both survivors and their significant others to bounce back or adapt successfully to challenging or threatening circumstances (Hunter, 2001; Walsh, 2003). It is evident in the sociological literature regarding adults who face adversity of uncertain course and duration, such as hospitalisation, that they seek to construct norms and systemise information as a means to establish current and future states (Comaroff and Maguire, 1981). For disruptions caused by chronic illness Williams (1984) refers to this process as 'narrative reconstruction', where individuals employ strategies to re-establish order from the chaos and fragmentation caused. Similarly, Bury (1982) and Charmaz (1987) identify this phase from biographical disruption as 'biographical repair'. This involves individuals mobilising their resources in an attempt to normalise, whilst also using sense-making processes to renew their self-identity (Bury, 1982; Charmaz, 1987). Although this literature focuses on the individual in navigating from a state of disruption, it was evident from the study findings that survivors and

families appeared to mobilise their resources in order to focus on achieving a desired normalised state.

Narrative disruption and flux

Narrative construction and reconstruction have been considered within the literature as a product of time and the research process as opposed to the illness experience in isolation (Bury, 2001; Charmaz, 2002; Lawton, 2003). Therefore, other potential explanations for disruptions need to be considered. In addition to the narrative content, disorder within and across stories could be attributed to the temporal nature of the longitudinal data collection process. Mattingly (1994, p. 605) states that 'we make as well as tell stories' and, therefore, time could have given rise to accounts evolving, changing, being retold and contradicting former stories. In the context of this study and relating to the central participants, childhood and adolescence are a time of personal, physical and social change (Christie and Viner, 2005). Much has been reported in the literature with regard to certain periods of childhood exposing individuals to inherent adversities, complexities and stress (Arnett, 1999), irrespective of whether they have been exposed to PIC. This has been termed by Hall (1904) in relation to adolescence as a period of 'storm and stress'. Buchanan, Eccles, Flanagan et al. (1990) suggest that this is due to numerous difficulties faced such as conflicts with parents, mood disruptions and risk behaviours. Therefore, survivors' own development may provide novel lenses to view their world. Subsequently, new or alternative insights that emerge and re-emerge through and within the stories told may contribute to this chaos.

Possible explanations for the observed divergence and chaos could also be attributed to the linguistic and narrative proficiency of participants. Narrative and discourse abilities are affected by cognitive and linguistic processes and abilities (Chomsky, 1968; Leman et al., 2012) as well as social and emotional development (Leman et al., 2012; Nelson, Aksu-Koç and Johnson, 2013). Therefore, collectively, both individual and social-communicative dimensions (where individuals learn to establish positions and roles during interaction) appear influential. In this study, survivors and significant others formed a heterogeneous group that varied in chronological age, health status, developmental level, and linguistic ability. Although not an exhaustive list, Nelson et al. (2013) recognise

that these factors may be influential in how stories and experiences are viewed, constructed and told, or concealed. In addition to varying ages, many of the survivors had a predisposing or subsequent chronic illness. Garrison and McQuiston (1989) report that children and adolescents who experience chronic illness can have impaired development due to the restrictions that are imposed upon them, such as absence from school due to hospitalisation. Furthermore, despite various platforms being available for participants to tell their story, linguistic competence may have contributed to the complexity of their stories due to difficulties in articulating or sharing meanings. Certainly, for some survivors, neurological trauma may have resulted in linguistic deficiency which Faircloth, Boylstein, Rittman et al. (2004) propose as resulting in impaired biographical flow more so than a biographical disruption.   However, within the context of this study, orthodox theories (such as Piaget and Erickson) could be limited as they have been predominantly developed and tested on children defined as 'normal'. It could be argued that the children who participated in this study may not conform to this homogenised perception of 'normality'[36], thus challenging the appropriateness of applying such theories.

McAdams (2001) suggests that narrative identity is a dynamic story of the self. He proposes that the concept of identity is constantly changing, as individuals begin to organise their lives within society. However, McAdams and Cox (2010) state that these 'stories of the self' begin to develop in late adolescence. Therefore, for those survivors in childhood as opposed to adolescence, the meanings and values attributed to narrative imagery and chapters could have been restrained by their developmental ability and potentially unrefined cognitive and linguistic skills (Habermas and Bluck, 2000; McAdams, 2001). Variance in these underpinning processes could have also contributed to the chaotic and complex stories told.

Collectively, it is evident that multiple factors, such as the storytelling, uncertainties, and social stigma, appear influential in the disruption and flux PIC survivors experience and construct as part of their long-term psychosocial well-

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[36] For instance: James had a conduct disorder, Andrew was born profoundly deaf, Katherine was raised in a different country by her grandparents and had experienced a haematological condition prior to her critical illness.

being. As individual survivors and as family units, there appears interplay and mediation in navigating this state which alludes to the resilience of survivors and their significant others.

8.3.3   Long-term psychosocial well-being: an inter-relational and dynamic entity

Findings from this study also suggest that long-term psychosocial well-being is constructed and experienced by PIC survivors as an inter-relational and dynamic entity. Findings illuminate that, for most survivors, psychosocial well-being was constructed as a complex, vibrant and, for the most part, dynamic state. Interestingly, as will be discussed further in section 8.3.4, these findings do not propose a single trajectory of survival that illuminates the course of psychosocial well-being from six to 20 months post critical illness. Instead, dynamic and evolving constructions of well-being emanate from an inter-relational and fluid state that transcends individual, social and societal domains. This finding is supported by Sarup (1993) who identifies that meanings are derived beyond micro-scale processes of human interaction. They are active and unstable, and pivot between political, cultural and ideological progress (Sarup, 1993). The development of self is seen as a sociological concept constructed by interactions with others (Clarke and James, 2003) and, as such, how children and young people discussed their condition with others and how they negotiated their identity was seen to influence their developing biography. Inter-relations involved significant others, wider social groups as well as former lives and biographies. Similar to paradoxes alluded to in section 8.3.1 (page 264), inter-dependence with others both threatened and preserved survivor well-being. Despite similarities and contextual homogeneity, disparities exist between survivors' stories and the significant others within their lives. This conforms with the statement by Faircloth et al. (2004, p.244) that 'not all physiological illness or disease will have the same impact on people's lives' and alludes to the different lenses used to perceive, experience, and story the same phenomena.

Divergence in relation to survivor expectations and choices from those within their social group provoked conflicts, stigma and concerns. Findings illuminated interplay in meanings ascribed to experiences and how these were reported between PIC survivors and their significant others. However, it was also evident

that adults within survivor lives required survivors to report 'factual' stories. Previous literature does recognise variance in the inter-rater reliability of parent reports compared to children's reports of well-being (Eiser and Morse, 2001) and therefore confirms that different perspectives of their experience are reported. Furthermore, parental accounts dominated by pathologised notions of their child's PICU experience have been previously illuminated in a study by Atkins et al. (2012). Attributed to the rarity of childhood critical illness, Atkins et al. (2012) acknowledges that this intrinsically isolates survivors' families and disables them from integrating with other people who could facilitate normalising their experience and therefore their language. Subsequently, this instils parents with feelings of isolation and no clear pattern for their recovery.

The pathologising of storied experiences was not the only divergence between survivor and parental accounts. A focus on the temporality and accuracy in the sequence of events and experiences took priority in parental narratives. This contrasted with some of the survivors' chaotic and complex stories that did not follow an orthodox temporal pathway. Instead, survivors' accounts flitted between and interwove many experiences and events within and across each story. Subsequently, findings display that, in some cases, the complexity of survivor stories was dismissed, interjected or overruled by some significant others as greater value was placed on an objective and coherent story.

The experiences of significant others identify the family as fundamental to maintaining survivor well-being through protection. However, the uncertain trajectory of chronic critical illness can expose family members to heightened levels of psychological distress (Hickman Jr and Douglas, 2010). This was evident in the context of these survivors' lives. Family members concealed distress, negative thoughts and concerns in an attempt to protect each other and survivors. Although Hickman Jr and Douglas (2010) propose that psychological symptoms often dissipate over time, a significant proportion of family members will remain at moderate to high risk of psychological distress after discharge from the intensive care unit. This distress was evident in significant other stories at up to 20 months post critical illness.

Analysis of significant other stories identified a unified dependence across survivor and significant other stories. The survival of the children was perceived as central to carer and sibling well-being, with enhanced kinship reported. Against imagery of conflict, stigma and concern, inter-dependence in the family unit for maintenance and protection of well-being was evident. This was bi-directional as both survivors and their significant others alluded to a dependence upon each other, thus illuminating the different lenses in which the world is perceived, interpreted and constructed within the same context. Although hidden and public selves were evident in the construction of survivor selves, this was also evident in a relational perspective between significant others within the case. Interestingly, for siblings, this centralising of the survivor in the family formation defined their status in relation to roles and identity within and outside of the home. Care-giving and protective statuses were apparent in their own and the survivors' accounts of them. Invariably their narrative also evolved from biographical disruptions through trauma, unknowns and concerns, which endured long after the critical illness event. Unlike some reports within the literature (Wilkins and Woodgate, 2005; Alderfer, Long, Lown et al., 2010; Knecht, Hellmers and Metzing, 2014) in relation to sibling functioning, this did not result in stories of injustice, jealousy or envy towards the survivor. Instead, gratitude and enhanced kinship emanated through the stories where siblings were included such as in the cases of Tim (section 6.2, page 180), James (section 6.4, page 192), Clare (section 6.5, page 199), Steve (section 6.6, page 205), and Ollie (section 6.10, page 225). Subsequently, sibling identities were constructed through their narratives as agents of protection, through concealment, care and promoting health.

Social comparison as means of understanding

As part of what could be described as sense-making processes within the narratives of survivors and their significant others, other children, events and experiences were used as calibrators to establish and situate their own status and standing in the world. Findings confirm that PIC survivors recognised other children, such as peers, and families, such as relatives, as worse off in life. Therefore, a process of rationalising occurred which revealed their former, current and future lives as 'not as bad'. This finding appears to align with Festinger's (1954) Social Comparison Theory which proposes that individuals evaluate their

beliefs and abilities through comparison with others. This theory has subsequently been applied to individuals who have experienced life crises and is recognised as an effective approach to coping with loss and trauma (Filipp, 1999). Specifically, it is evident that Will's (1981) Downward Comparison Theory has most alignment with the findings from this study. This theory proposes that individuals make downward comparisons, such as comparisons with those less advantaged, in order to improve self-esteem. This theory suggests that selective comparison processes are effective in positively influencing an individual's interpreted reality following threats, loss or traumas. Although Wills (1981) theory appears somewhat ruthless and egocentric, this was not how it manifested in the survivor stories as they identified pity and sadness for others, as well as joy for those that had recovered. Furthermore, individuals seek out others who share their opinions and abilities for comparison because accurate comparisons are difficult when others are too divergent from oneself (Festinger, 1954). Individuals who have been exposed to life crises may attempt to calibrate themselves with similar others, evident in findings from the survivor narratives. However, for some it was not possible as, due to geographical and social circumstance, they were not in contact with others that had survived similar critical illness events, thus exposing them to additional psychological adversity.

Leading on from social comparisons, it was also evident that perceived or realised stigma or victimisation manifested from their critical illness, in particular in places of education and in interaction with peers. This was not limited to survivors, as significant others also reported stigma. Imagery of stigma related to their perceived physical and psychological vulnerability towards others, their status as different due to having to take medication, or just being different in relation to other children. This imagery was associated with actual or perceived loss over situations and others and ultimately a loss of status, value, control, and possible self-esteem. For example, in Katherine's story (section 5.7.1, page 148), she had to be put back a year in school due to her poor attendance whilst she was ill in hospital, a matter which was out of her control. However, she reports how her peers reacted to her with inquisition and assumptions in relation to her new status as being in the class below them. In this case, it is evident that Katherine retorts with downward comparisons by constructing her peers as naïve or immature.

It was evident that hidden selves were not contained to peers' identities, as concealment was apparent within the family unit and in data collection visits. Contained identities were particularly apparent with survivors who engaged with traumatic imagery, such as Steve (section 5.6.1, page 140). Non-disclosure of certain imagery or events emanated from concerns about causing harm to those significant around them. For some survivors, such as Sarah (section 5.3.1, page 118), this concealment related to the illness identity they had acquired or were more aware of since their critical illness event. Although not specifically reported in the PIC population, concealment has been identified in children with chronic health conditions. Certainly, for the majority of the PIC survivors in this study, residual health problems manifested following their critical illness. Christian and D'Auria (1997) explored conceptualisations of chronic illness and related life events in adolescents with cystic fibrosis. Their findings identified that adolescents used protective strategies in order to reduce their sense of difference from their peers. This involved keeping secrets about their illness, hiding visible differences, and discovering a new baseline. Collectively, this resulted in jeopardised relationships by creating distance with peers who were then unable to appreciate their condition (Christian and D'Auria, 1997). Furthermore, the Atkin and Ahmad (2001) study recognises that children cope with thalassemia or sickle cell disorders by using strategies to minimise 'difference'. Threats to normality are navigated through negotiation and engagement with intrinsic and extraneous factors (such as individual resources, chronic illness management, social identity) with varying perceived effectiveness (Atkin and Ahmad, 2001). In contrast, for two of the PIC survivors in this study, Andrew (section 5.8, page 156) and Katherine (section 5.7, page 147) who also experienced chronic illness, they instead openly challenged their peers.

In relation to the wider social group, stigma and conflict were evident, thereby provoking survivors to contemplate their social standing. Survivors recalibrated and, in some cases, concealed their selves in order to conform to the expectations of others. This finding has been reported by Blakeney, Robert and Meyer (1998), who explored survivors of physically disfiguring trauma. They identify that burns survivor's experience a series of assaults on the mind as well as on the body that present extraordinary challenges to human resilience. The injurious event itself is traumatic, while physical changes in the survivor's body are permanent reminders

of the fear, horror, sadness and pain experienced. Furthermore, the reactions of others provoked ongoing trauma through feelings of rejection, isolation, and humiliation. Although findings demonstrate that most of the survivors in this study did not experience physical scars from their critical illness, restriction to routines (such as medications) was tackled by survivors with concealment or avoidance. The act of concealing disability to 'pass as normal' can involve considerable tensions and difficulties in managing interactions (Charmaz, 1983) as social support from significant others is a critical determinant of self-concept.

Gendered stigma

Although stigma featured in virtually all survivor stories, Williams (2000) and Prout (1989) identify that the navigation of stigma is dependent upon gender. For boys, illness is an isolating and threatening experience as 'being physically fit and tough was highly valued and that sickness… was a stigmatising form of weakness and incompetence' (Prout, 1989, p. 350). Findings from this study confirm this gendered perspective as, predominantly, the male survivors professed orthodox masculine imagery in relation to their self and social identity following the critical illness event. Constructions of physical fitness and strength were posed against narratives of illness and psychological trauma. One of the main coping strategies which Goffman (1963) described as being used in this situation is 'passing', which entails trying to pass as 'normal' with the constant risk of exposure. Furthermore, from the within-case analysis, this appeared reinforced by hegemonic masculine narratives and expectations from survivors' fathers. In contrast Prout (1989) proposes that, for girls, illness is approached differently with friendship groups being used as supportive network. Although this was evident in one of the survivors (Claire), where she mobilised her friendship group to support her transition from an ill to a recovered state, this was not evident in the other female survivors. The other female survivors were exposed to perceived stigma as well as chronic health impairment. Therefore, they navigated stigma through more orthodox masculine strategies, as outlined by Prout (1989). This could be explained by what Goffman (1963) distinguishes as whether or not the stigma were discredited (obvious to others) or discreditable (could be hidden from others), as this dictates how they are navigated. Findings identify that, for the female survivors, the types of stigma did vary. For example, Katherine experienced

discredited stigma due to observable changes to routine (change in school year) and body image (loss of hair), whereas Sarah experienced discreditable stigma as she had the option to conceal her asthma from others. This could explain why the female survivors' responses to stigma varied and certainly, if more older female survivors had been included in this study, this might have become a dominant narrative theme.

Familial and wider social stigma

Findings identify that stigma were not just contained to individual survivors. For the family, newly-emerging stigma and enforced changes to social identities were experienced. Certainly, as time progressed from the critical illness event, greater emphasis was placed on the social rehabilitation and identity transformation. This finding is supported by Carnevale (2007) who acknowledges that families of children with long-term ventilation involved complex social phenomena. He recognises the 'striking' family distress that was related only partially to the child's significant medical problems. Most difficult problems encountered by families related to the reactions and attitudes of others: extended family members, friends, community members and healthcare professionals. These families felt rejected and marginalized by the society in which they live (Carnevale, 2007). Similar stigma were recognised by significant others in relation to their child or to themselves. Parents' and certainly fathers' roles in dealing with their child's stigma appear absent from the literature. However, Williams (2000) identifies that mothers mediate on behalf of their children in order to minimise stigma, thus enabling them to 'pass' successfully in public by anticipating and negotiating situations. In this study, minimising was not as 'clear cut' in parental narratives as ambiguity and lack of direction regarding the best course of action emanated from their stories. For example, in Ollie's case (section 6.10, page 225), his father observes Ollie experiencing peer stigma. He debates the impact that intervening and removing Ollie will have on Ollie now and in the future. His father tells of his decision to leave Ollie to endure the stigma, but then doubts his decision.

Collectively, it is evident that the long-term psychosocial well-being is experienced and constructed by PIC survivors within the context of their own lives as an inter-related entity, informed and defined by family, social and societal worlds. Furthermore, it is evident from the study that psychosocial well-being is a

dynamic state, transforming and evolving over time and between individual and social worlds.

8.3.4 Re-conceptualising long-term psychosocial well-being

From the aforementioned discussion of how PIC survivors describe, experience and construct their long-term psychosocial well-being, novel insights that challenge previous conceptualisations are posed.

Most evident from the findings of this study is that survivor constructions of long-term psychosocial well-being are not neatly and coherently situated. They are instead influenced, changed and determined by a reported multitude of exogenous and extraneous factors. Therefore, how psychosocial well-being has been constructed by PIC survivors within the context of their lives is not clearly delineated. Although this study explored constructions over a longitudinal period (bar one survivor), clear delineation of stages of adaption or adjustment was not captured. Lau and van Niekerk (2011) confirm this finding in their study on the experiences of burns survivors. They report general themes inferring the phases experienced as opposed to a clearly-defined trajectory. Study findings do not appear to 'fit' cleanly into any of the pre-defined theories that attempt to articulate survival trajectories, as outlined in Chapter Two (pages 14 and 21). This lack of fit is predominantly due to the linear structure and distinct pathway of survival conceptualised in the literature. Conversely, accounts were messy, chaotic and complex. Existing explanatory mechanisms do not appear to comprehend the interplay between physical, social and psychological worlds. The study has identified paradoxes, sometimes even contradictory constructions of well-being, from the same individuals, within-cases and across instances. Although the findings do align to what Atkins et al. (2012) describes as a focus on the 'new normal', this does not encompass the chronic nature of ill-health that was evident for the majority of survivors in this study. Instead, insights from this study allude to the reciprocity between individual and social worlds, which are interrelated and influential on each other. Certainly, from these survivor stories, oscillation between worlds appeared dominant and survival of critical illness was not the end but the beginning in their trajectory. Furthermore, not all the children and their significant others identified themselves as recovered, as their lives were disrupted

or in flux. This inferred a state of liminality, which has not been recognised in previous theories.

It is evident that existing models and theories are PICU-centric and driven by a desire to ensure that medical interventions do no harm. They do not feature the multiplicity of events, experiences and adversity that may evolve following the critical illness event. As 60% of children that survive critical illness experience ongoing morbidity (including chronic illness or disability), it is pertinent for theories to comprehend this complexity. Upon re-engaging with the broader theoretical literature, it was evident that a number of explanatory mechanisms have been proposed that may be applicable to PICU survivors and their long-term psychosocial well-being. Specifically, frameworks that provided explanations wider than the biomedical domains were considered.

Jillings' (1990) life-threatening illness model as applied to children by Davenport and Rice (1995) provides an holistic and dynamic comprehension of survival, as shown in Figure 19 (page 285). Although the model was initially developed to direct nursing care (Davenport and Rice, 1995), the concepts proposed appear to align to findings from this study. The model suggests that family and individual characteristics, as well as the child's response to the life-threatening illness, are inter-related and influential. It also identifies that the survivor's illness biographies and wider social influences, such as culture and ethnicity, contribute to illness response, which the aforementioned theories omit. However, it does have limitations in relation to its application to understanding this study. The accounts presented in the wider biographies of survivors were influential in informing constructions of well-being and this is omitted from this theory. Furthermore, wider social groups such as peers were significant in defining and influencing psychosocial status. This is also absent from the model.
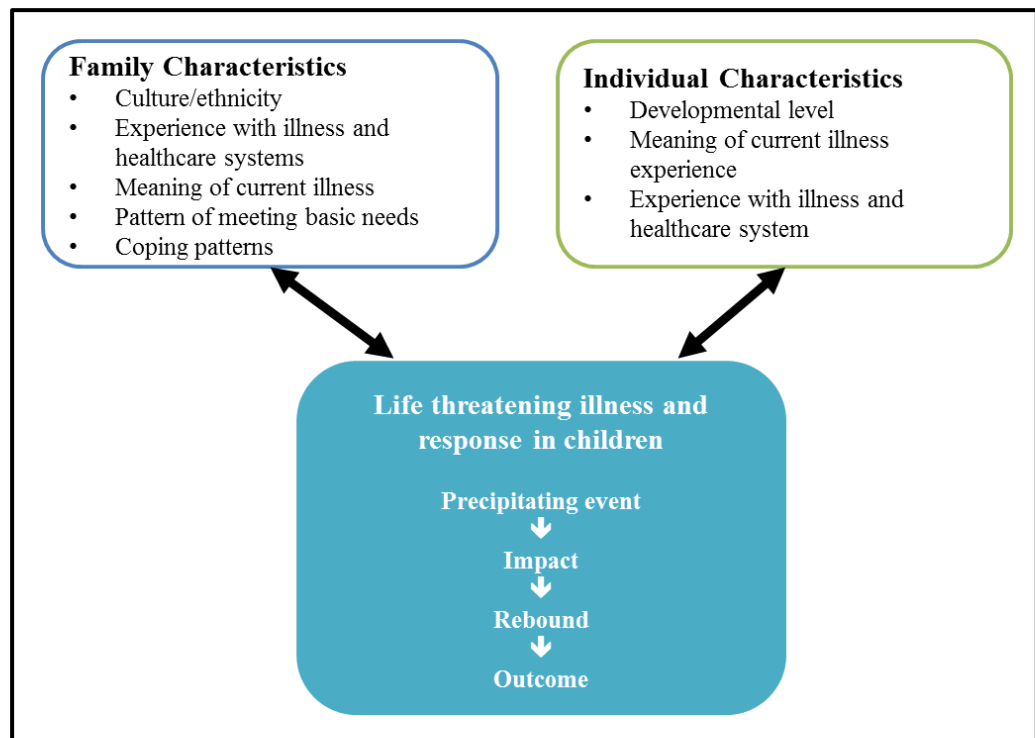
Figure 19: Davenport and Rice's (1995) Life threatening illness model

Bronfenbrenner's (1977) ecological model (shown in Figure 20) provides an explanatory framework for the inter-relation of how well-being is constructed by PIC survivors. His theory comprehends the influence and interplay between children's experiences in one part of their lives on other aspects of their development and conduct in other facets of their lives (Aldgate, 2010; Leman et al., 2012). Therefore, this model comprehends the interrelation between individual, social, societal, and historical domains of an individual's life and experiences.

In a similarly holistic comprehension, Aldgate alludes to the multi-layered and multi-faceted nature of this perspective by stating, '… children are surrounded by layers of successively larger and more complex social groupings which have an influence on them….Children across the world will experience childhood in many different ways. ' (Aldgate, 2006, p. 23).
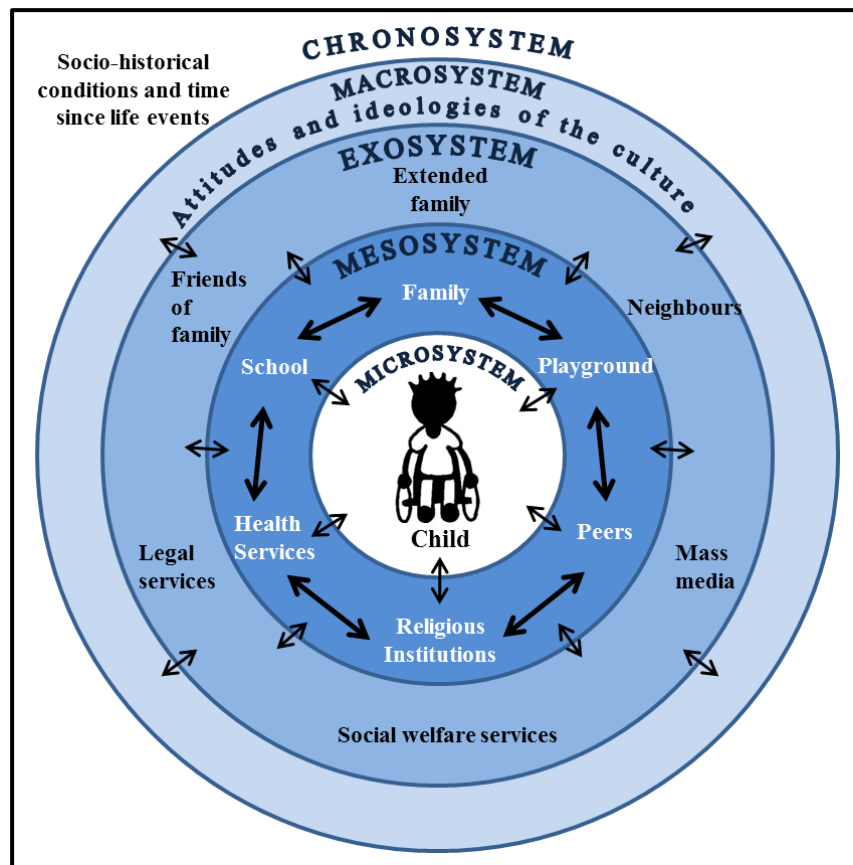
Figure 20: Bronfenbrenner's (1977) ecological model of development[37]

An ecological conceptualisation of development comprehends the nature (or biological factors) as well as the nurture (or contextual) factors that facilitate or inhibit development (Bubolz and Whiren, 1984). Moreover, the inter-relation between factors, such as history (chronosystem), culture (macrosystem), social groups (exosystem and mesosystem) and self (microsystem), is recognised as influential in the development of cognitive, psychological and social competence as well as other experiences (Bronfenbrenner, 1986; Christensen, 2010; Leman et al., 2012).

Despite being developed to conceptualise child development, there is scope to use this perspective as an alternative framework for exploring survival following PIC. The ecological perspective allows for deficits identified in the existing research to be considered, namely: comprehending children's past, current and future experiences; the interplay between facets of survivors' selves and lives; and

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37 Adapted from Garbarino, J. Sociocultural risk: dangers to competence. p. 648. In: Kopp, C. and Krakow, J. (Eds) Child development in a social context. Copyright (1982) Addison Wesley Publishing Company, Inc.

opportunity to understand the context of meanings ascribed to experiences. Collectively, this could provide a more comprehensive insight into long-term psychosocial well-being of PIC survivors whilst maintaining the centrality of the child within the inquiry. Narratives alluding to a multiplicity of layers and experiences in storied form refer to the interplay between layers of social and personal selves. Therefore, the ecological model provides a platform against which to set the assertions of the quintain as shown in Figure 21 (page 288). It allows for the dynamic movement of constructions of psychosocial well-being to be liberated, not just within a single dimension, but also on multi-dimensions.
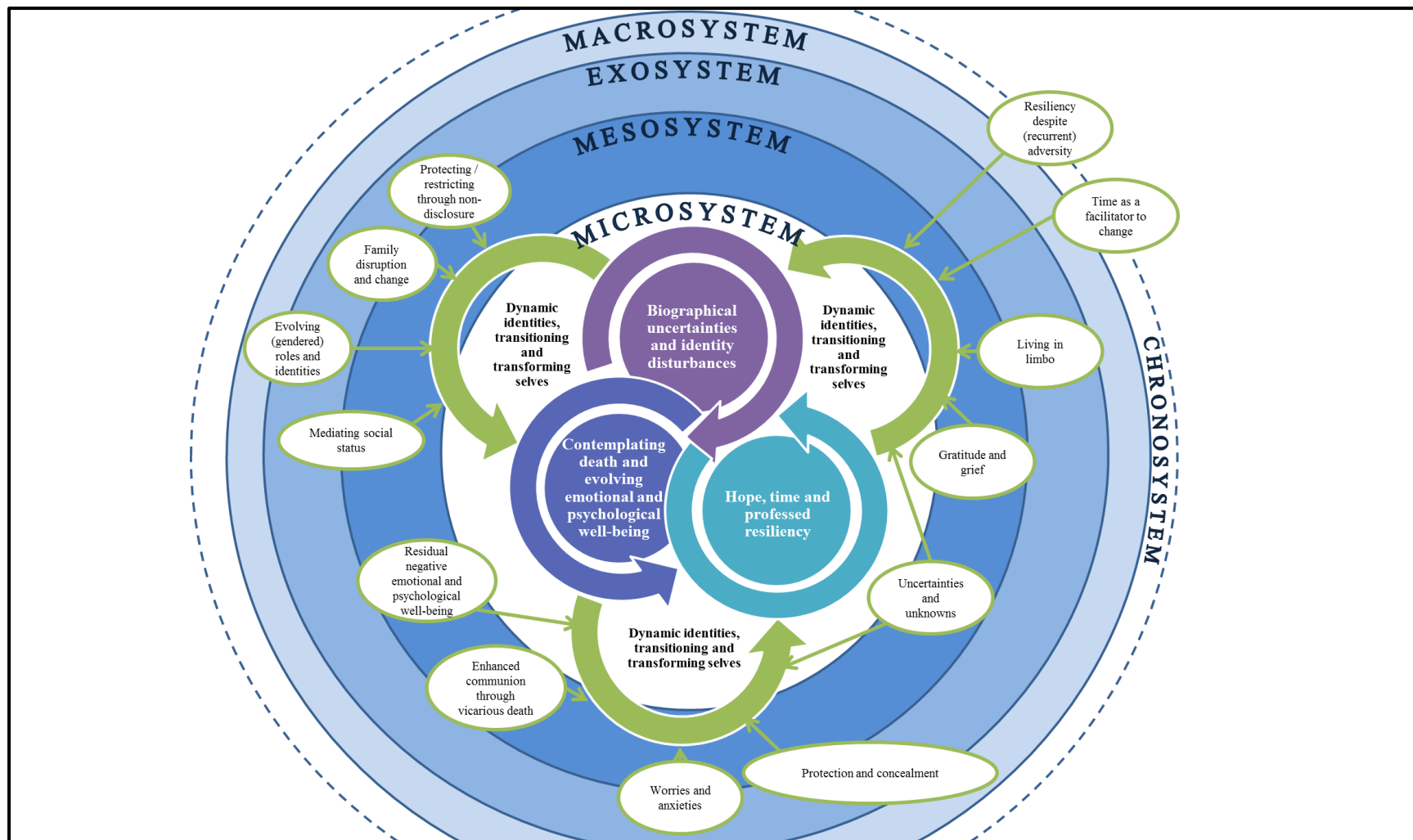
Figure 21: Conceptual framework of long-term psychosocial well-being of PIC survivors within the context of their lives

8.4 Reflexivity and methodological considerations

As the first study to explore PIC survivors' long-term psychosocial well-being within the context of their lives, a number of personal and methodological insights have been illuminated. The most critical discernments relate to the situationality of the study, researcher and participants, which will now be discussed.

8.4.1 (Re-)situating the study

From the outset, this study bore the label 'exploratory', which was reflected in the qualitative strategy of inquiry employed. However, this status was challenged by a number of insights gained during the course of data collection and analysis. As identified in section 8.3.1, PIC survivors constructed both public and hidden notions of psychosocial well-being. These stories were co-constructed with an audience. In all cases this was with myself, as the researcher, but on many occasions also with other people such as parents and siblings. It became evident through these encounters that previously undisclosed stories were being told. In some cases, disclosure provoked revelation to both the survivor and their audience. This motivated me to consider the status of this study. I contemplated whether, if survivors had not participated, certain stories would have remained untold and, therefore, not provoked a response? This insight challenges whether the study was unintentionally a type of intervention or bore a dual citizenship of both the exploratory and interventional realms.

8.4.2 (Re-)situating the researcher

Exploratory vs. therapeutic roles

Synonymous with the situationality of this study was also my position as the researcher. Extensive reflection and contemplation illuminated how my status, role and responsibilities evolved and were re-defined during this inquiry.

As referred to in Chapter Three, the term 'narrative' has been applied and utilised in a number of disciplines and academic subjects as a research methodology, method, analytical framework, as well as a form of therapy (Clandinin and

Connelly, 2000). The intention from the outset of this study was for the interview encounter to be a platform on which an in-depth understanding of the phenomena could be constructed. This positioned my role as active, a vehicle by which participants' experiences were co-constructed, interpreted and revealed (Riessman, 2008).

From the outset of the study, I openly disclosed my own identity through dialogue and physical appearance. This included an identity as a children's intensive care nurse in the East Midlands region, and as a white, British, adult male. I was, therefore, aware that this disclosure might have influenced how participants responded in relation to constructing their story. This could have influenced the story's content, leading the survivor to focus on aspects of their story that they thought the researcher wanted to hear. On the other hand, it could have also facilitated openness, through shared knowledge or understanding between the researcher and survivor, such as describing places and medical terminology that were familiar to both.

However, during the study, some survivors (such as Ollie, page 172) challenged this status as they viewed our interaction as therapeutic or defined study visits as part of their recovery. This provoked uncertainty and substantial reflection, as outlined in the researcher reflexivity in Chapters five and six, over whether I had the skillset to safely mediate this role. Similarly, it provoked concerns brought by this additional responsibility, causing apprehension about not exploiting or misleading participants. These insights confirmed the importance of reflection in action during the study period and seeking guidance from experts. Moreover, it identified potential deficits in provision or ability to access counselling or therapeutic services post-PICU discharge.

The researcher as a witness

During the data collection and analysis stages of the study, I was exposed to insights, events and stories that I was not expecting to occur. Through my observations as well as through the co-construction, insights were illuminated. Certain occurrences resonated particularly loudly. The detailed accounts as well as stories that were unsaid alluded to adversities and prosperities of survival and contemporary life. These insights provoked me to reflect on my own history and

experiences and heightened my awareness that my role was as much a witness as well as a vehicle for discovery. Being present and bearing witness have been widely explored and practised by health professionals (Cody, 2007; Mitchell, 2009). However, as acknowledged by Schick Makaroff, Sheilds and Molzahn (2013), listening for the unsayable and understanding that what is significant cannot always be expressed, is a less refined skill. Certainly, during the data collection phase, I was exposed to situations that challenged my perspective. Flewitt (2005) acknowledges the dynamic role that develops during the data collection process between the researcher and participants. She reflects her own longitudinal ethnographic research that 'my role as researcher is blurred in the homes, where the mothers and I seem to be in a new kind of social 'bubble' somewhere between acquaintance and a friend' (Flewitt, 2005, p.561). This statement certainly resonates with my own status as a researcher within this inquiry. However, unlike Flewitt, I feel that my dynamic role was not contained within the participants' homes, it continued to be transformed during the analysis, and in writing this thesis as new insights continued to emerge.

8.4.3   Situating the survivors

A primary objective of this study was to provide a platform for PIC survivors' voices. Therefore, the research strategy and methods employed focused on liberating storied experiences and maintaining the survivors' centrality to this inquiry. Through undertaking the study, a number of insights relating to the position of the survivor were highlighted in relation to the interview encounter, the analysis, and representation (in the thesis).

The interview encounter

From the interview encounters, it was evident that the survivor stories were co-constructed. All stories were told to an audience, which for most included loved ones (such as siblings and parents). However, it became apparent that survivor encounters were situated on a spectrum of co-construction. This aligns to what Riessman (2008) identifies as some narratives being more influenced by the audience than others. Therefore, as identified in the discussion, the audience could have been influential in the content of the narratives (as discussed by Duncan, Drew, Hodgson et al., 2009). However, findings also identified that the audience,

including myself, were involved in the creation of the narrative. This appeared to be influenced by a multiplicity of factors, which were not only limited to age or linguistic/cognitive ability.

In conjunction with the transformation in my researcher identity, I recognise that during the study I developed more refined research knowledge and skills as well as a greater reciprocity with the participants. This was reflected in the interviewing technique used (Rubin and Rubin, 2005), as I developed the confidence to rephrase questions and probe during the course of the data collection. These more refined skills could have liberated more cohesive accounts toward the end of the study period while the lack of them could have impeded such accounts at the outset.

Furthermore, as reflected within the findings' chapters, for some survivors the audience acted as triggers for engagement in the interview. The benefits of audience engagement, specifically maternal scaffolding, have been recognised in the literature, as providing richer and more complete narratives than when a child's recall and story are unprompted (Irwin and Johnson, 2005). It was evident that fathers, mothers, and I provided scaffolding and support for the survivors in this study to narrate their stories. This required me to adapt to varying levels of co-construction to align with the survivors' differing positions. However, it was evident that parental involvement in the construction of survivor narratives was pivotal for engagement. Insights identify that some survivors (such as James, page 123), used other people in sophisticated ways as adjuncts for communication, whilst maintaining control and their own centrality in the interview. Moreover, the position at which survivors were situated on the co-construction continuum was not static. Survivors' standings (such as confidence, ability and participation) evolved and developed during the data collection, which provided an additional dimension to their stories.

Co-construction also varied in relation to the data-collection methods used. Preference for art-based or verbal approaches by survivors provided variation in how the stories were constructed. This reconfirmed the flexibility necessary for research with children but also posed practical, ethical, and analytical challenges, namely maintaining of authenticity in the narrative. However, it became evident during the data collection phase that an emphasis on parity and inclusion appeared

more important than any challenges faced with regard to employing the methods. For survivors who had previously been excluded from research, their involvement and attempting to liberate their story was paramount. Therefore active co-construction was dependent on their needs as opposed to a focus on replicating methods and the researcher to ensure consistency across the cases.

The analysis

Survivors in this study varied in chronological age, developmental level, and linguistic, cognitive and physical abilities which posed challenges as to how the data were analysed. This generated a challenge for the research process in terms of maintaining a personal narrative from co-constructed data. Challenges in analysing narratives have been reported in the literature, relating to the incongruence between the practical process of analysing data (and ensuring quality) and maintaining theoretical or ethical standpoints (Emden, 1998). Mishler (1986) identifies the difficulties of delineating the boundaries of a story in relation to interview data. This was evident as the narrative was constructed longitudinally and co-constructed with the audience (such as parents). Polkinghorne (1995) suggests that the way in which the narrative is formed depends on the particular perspective of the researcher or the interests of the discipline. As the purpose of this study focused on the surviving child or adolescents' experiences, their voice (through language or images) remained central. Therefore, a reciprocal process of immersing and re-immersing in the constructed narratives was undertaken to ensure that the child/adolescent's story was dominant. This involved reading the transcripts as a whole, prolonged engagement with the narrative content to clearly identify the imagery and themes, writing the narrative in full and exposing this to critical review by PhD supervisors.

A further methodological insight from this inquiry is the application of narrative psychological analysis (Crossley, 2000; McAdams, 2008) in the exploration of children's psychosocial well-being. I applied this analytical method in its most elementary form to structure the holistic-content analysis of verbal and visual data to understand participants' psychological and social worlds. The application of narrative psychological analysis to explore children's narratives remains scant within the literature. This could be explained by McAdams assertion, based on Erikson's theory, that the development of ego identity is pivotal to this approach

(McAdams, 1989; McAdams, 2001). Erikson (1995) proposes that the fifth out of eight stages of development is achieved in adolescence or early adulthood where individuals face confusion about the integration of their identity and role. This is reported to provoke the combination of disparate roles, thoughts, and social activities into a purposeful psychosocial collective (Breger, 1974). This transitional stage identified as developing identity is based on Freudian theoretical influences and the development of sexuality in adolescence (McAdams, 2001). It is suggested that this physical, hormonal and self-concept change provokes an evolving narrative that has a childhood past and an adulthood future. Furthermore, McAdams asserts that formalised operational cognition provides resources for the contemplation of identity (McAdams, 2001). Therefore, this approach has been predominantly used with stories from linguistically competent adults (McAdams, Diamond, de St Aubin et al., 1997; Crossley, 2000; McAdams, Reynolds, Lewis et al., 2001).

However, this study included survivors as young as six years of age. These findings dispute the notion that children outside of adolescence or before ego-identity do not possess an identity that can be illuminated through the narrative psychological analysis approach. This challenges the status quo regarding the perceived abilities of children and adolescents and the prisms through which they view the world. Through verbal, non-verbal or visual data, all participants provided profound, evocative and insightful contributions that related to their life stories. Furthermore, this insight contests whether being exposed to a life-threatening event provokes contemplation of roles, identities and the situating of oneself in society from a younger age. Alternatively, data collection methods utilised, particularly the art-based approaches, illuminated self and social identities in younger children that could not have been accessed linguistically.

Representation

Throughout this study, I was acutely aware that the collaborative ethos should pervade all stages of the research. This was reflected in the data collection phase through the interview encounters. Ownership of the information created during or outside of these interactions was not assumed. However, on the occasions that I requested to use the information, such as the photographs and drawings, participants responded very keenly and consented to its use. Despite the

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survivors' willingness to share, I was aware of the enormous responsibility in interpreting and representing this information. Fine (1998) identifies that qualitative researchers need to be aware of their own power and she cautions not to idealise stories when writing about those who have been 'othered'. Therefore, throughout this thesis, I have been explicit about the role of my own lens in representing the survivors, such as 're-storying'. The authenticity of the analysis was enhanced by researcher reflexivity, which was used in order to clearly situate myself within the construction and interpretation. Furthermore, to provide greater transparency of analysis to the reader, thick description, in the form of vignettes, and data excerpts, was presented.

Representing participants, particularly visually, posed challenges. This has been articulated by Christians (2005, p.136) who states,

> 'Pseudonyms and disguised locations are often recognized by insiders. What researchers consider innocent is perceived by participants as misleading or even betrayal. What appears neutral on paper is often conflictual in practice.'

Being aware of striking representational balance, prior to the interviews and construction of information, I explicitly stated the grounds on which I would use the information. I explained to all participants were they to read their own accounts, they would most certainly be able to recognise them as their own, but that information that would identify them to others would be removed. However, in representing their accounts and information, I was informed by legal-ethical and moral standings. This framework mediated between maintaining participant confidentiality and anonymity, whilst suitably representing the stories of those who participated and wanted to have their stories told. This territory was not clearly delineated within the literature and therefore the participant representations, presented in this thesis, were exposed to peer review by my PhD supervisors.

8.4.4 Study limitations

This study has a number of limitations that must be acknowledged.

Information pertaining to those who chose not participate in the study was not collected and, therefore, comparisons with those who did participate cannot be made. Furthermore, less than half (n=9/20) of the proposed number of survivors were recruited to participate in this study. However, it is evident from the findings that the volume of data and depth of analysis have provided novel insights into the phenomenon. Achieving the full number of cases (n=20) could have undermined the exploratory and in-depth nature of the study. Therefore, it could be proposed that this study is strengthened by the rich descriptions of each participant's life were obtained. This resulted in many commonalities emerging across contexts and instances, the nuanced meaning that each participant attributed to their experiences was not lost and was given preference over generalisation.

Another limitation is the composition of the sample in relation to ethnicity, gender, and disease group. The participants lacked diversity in relation to ethnicity, potentially because of the absence of resources to translate information into languages other than English[38]. Furthermore, male PIC survivors and those who experienced neurological conditions were highly represented. Collectively, as individuals' meanings are informed by time, gender, culture and situationality, this lack of diversity in the sample could limit insights. Therefore, any conclusions drawn from this study must be tentatively applied to survivors not represented by the study participants, as they may construct long-term psychosocial well-being differently.

PIC survivors were central to this inquiry. A core aspiration of this study was to utilise a collaborative ethos in an attempt to harness PIC survivors' experiences and stories. Children and adolescents were actively involved in the development and design of this study, as well as through the data collection approaches. However, their involvement in the analysis of the findings was limited to selecting the information used and being provided with the transcripts of meetings to comment on. As reported by Flewitt (2005), and intimated throughout this thesis, adult worlds and perspectives can be different from those of children. I, as the researcher, am an adult and recognise that I view the world through a different lens, influencing how the analysis and findings have been formulated. It could,

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[38] As stipulated by the Research Ethics Committee

therefore, be perceived as detracting from the survivor's stories, and instead telling my own. Although I do not refute that insights that have emerged from the analysis are influenced by my own perspective, this has been undertaken critically and with method. I have been consistently committed to conducting a moral, ethical and relational inquiry of which this thesis is the product. Maintaining the quality of this study has been pivotal and, therefore, in order to maintain the authenticity and credibility, my reflexive thoughts and processes have been presented throughout this thesis. Furthermore, rich data excerpts, counter explanations and divergent accounts have been presented to provide transparency to the reader.

Finally, I was painfully aware of my limitations as a writer in bringing to life the rich and vibrant lives and stories that I witnessed during this study. The analysis presented in this thesis is a representation, my representation, through my own lens. Subsequently, participant data through excerpts, photographs and images have been presented in this thesis body as a means of providing transparency to participants' stories and the subsequent conclusions drawn.

8.5   Conclusion

To conclude, this study has explored long-term psychosocial well-being of PIC survivors within the context of their lives. Existing research has conceptualised PICU admission and critical illness as evoking adverse and residual physical, psychological and social outcomes in some survivors and their families. However, understanding how PIC survivors construct and experience psychosocial well-being in the longer term is absent from the literature This study attempted to address these deficits by employing a multiple qualitative case study approach, explored longitudinally, underpinned by an interpretivist-constructivist orientation. This study identified that PIC survivors experience vibrant and complex lives and are exposed to a multiplicity of events and circumstances. These temporal events occur prior, during and post critical illness and can expose them to both adversity and well-being. A non-linear pathway, which oscillates between biographical, individual, familial, wider social and societal worlds, appears to facilitate and inhibit psychosocial well-being.

This study has provided a number of original contributions to the literature, in relation to the long-term experiences and constructs of psychosocial wellbeing within the context of childhood survivor lives, which will now be expounded.

8.5.1   Novel contributions to existing research

Data findings

This study contributes to the literature through being the first UK-based longitudinal empirical inquiry that has explored PIC survivor psychosocial well-being from six to 20 months post-PIC discharge. It has provided a platform to illuminate and understand PIC survivor constructions and storied experiences of psychosocial well-being, which maintain the contextual richness of survivors' lives. Novel insights suggest that survivor biographical and wider social worlds are influential on PIC psychosocial well-being in the long-term. Positive aspects of survival have been harnessed with imagery of hope, enhanced kinship and family support being identified through survivor stories. This suggests that survivor and familial resilience manifest following critical illness and other adverse childhood events in order to maintain and support psychosocial well-being.

Insights from this study do not refute that the PIC event is for some significant. However, for many, it is merely a strand in a rich tapestry in which other life events and experiences interweave to construct psychosocial well-being. This contrasts to the reports of adult significant others whose stories conform to orthodox constructions of the iatrogenic harmful nature of the PIC experience and environment. This challenges the status quo and the egocentric dominance of the PIC event as pivotal in the subsequent construction and experience of psychosocial well-being in childhood. Nevertheless, the findings presented in this study identify that PIC survivor psychosocial well-being can be negatively influenced by multiple residual and newly-manifesting adversities, such as stigma, chronic illness, and anxieties and fears.

This study has provided a platform to liberate the voices and stories of the PIC survivors, which have previously been unheard. However, other under-represented voices in this field of research, such as those of fathers and siblings, have also been exposed. Although their stories were not the focus for this inquiry,

their narratives allude to outstanding psychosocial needs that require further investigation.

Theoretical insights

This study has provided contextualised and in-depth, qualitative insights which challenge existing theoretical propositions (outlined in Chapter Two) that conceptualise survival as linear and uni-dimensional. Although theory development is beyond the scope of this study, findings identify that psychosocial well-being is constructed and experienced by PIC survivors as multifaceted and dynamic. Furthermore, findings demonstrate that long-term psychosocial wellbeing does not manifest in a distinct pathway. Instead survivors appear to construct and experience an undulating and oscillating trajectory that involves individual, biographical and wider social influences which is nuanced across contexts. That said, core themes and experiences identified from the accounts of survivors, and their significant others, appear to pervade the systems identified in the ecological model (Bronfenbrenner, 1986). However, this warrants further investigation and empirical work.

8.5.2 Implications for clinical practice, policy and future research

Implications for clinical practice and policy

From the outset, a fundamental aspiration for this study was to have impact on clinical practice and policy. The importance of impact was further confirmed through insights gained during the study itself, as a key driver for participation was to help other children and families. The stories presented in this thesis are powerful and evocative. Benner, Hooper Kyriakidis and Stannard (2011) confirm the power that narratives have on clinical wisdom and experiential learning, stating 'narratives reveal the emotional colourings in clinical situations' (p. 20). Therefore, rich accounts offer a powerful tool to provoke reflection and change, specifically in relation to children's nursing, where care is delivered amongst a multitude of stories (Carter, 2009). However, until now, children's and adolescents' stories of long-term survival have remained unheard by those who provide care. They, therefore, have tremendous scope to influence and inform the practice delivered, during PIC and post-PICU discharge.

Despite the majority of PIC survivors having residual illnesses, much of their contact with healthcare professionals focused on their physical needs. This suggests a mismatch between the holistic models of care (e.g. focus on health and well-being) that are claimed in policy (Department of Health, 2010), and how care is experienced or perceived. Expectations placed on health professionals to optimise patient contact, such as 'making every contact count' (Local Government Association, 2014), indicates that these findings have application to directing contemporary clinical practice. Health professionals need to reflect on their approach, conduct and actions, to ensure that the holistic needs of survivors and families are met.

This study has identified a number of novel themes that suggest outstanding psychosocial needs of PIC survivors within the context of their lives. These relate to trauma, re-adjustment and the social aspects of transitioning from critical illness that appear residual up to 20 months post-PICU discharge. Stories transcended organisations, times and locations and feature services from health, social care, education and the third sector. This suggests that this research has application beyond the confines of acute care. Certainly, for adversities such as stigma, greater collaborative working and education are required between sectors to ensure that PIC survivors and their families are adequately supported to achieve optimal holistic rehabilitation. The findings also highlight the need for national guidance and infrastructures to direct services and health professionals in delivering appropriate care in the longer-term. As a first step to achieving this, contact has been maintained with the PIC survivors who participated in this study in order to provide them with updates on progress (Appendix F). It is proposed as part of study dissemination, and in line with the collaborative ethos, that a stakeholder event should be held in Spring 2015 that will bring together PIC survivors, their families, clinicians, other stakeholders (e.g. educators) and commissioners. It is proposed that the findings of this research should be presented and discussed, with recommendations for local and national services and policy being developed collaboratively.

Recommendations for future empirical work

Maintaining an interpretivist-constructionist orientation, this study did not aim to make 'expert judgments' of the phenomenon. Instead, it attempted to harness and

provide a platform for survivors' voices, and those significant to them. In turn, this platform has illuminated how child and adolescent survivors construct and experience long-term psychosocial well-being. The stories told and the conclusions formed from individual and aggregate analysis allude to a multiplicity of elements, including but not limited to: cultural, familial, wider social and political strands, which warrant further exploration.

The small number of PIC survivors involved in this study was appropriate given the research objectives and its in-depth, exploratory nature. However, further research that draws on more diverse participant characteristics might shed light on other novel insights into this phenomenon. This is particularly important due to the ethnocentricity of those involved in this study.

Furthermore, longitudinal research spanning a timeframe greater than a six-month data collection phase is required in order to map children's journeys of survival more fully. Additional, in-depth qualitative research is also required to further unpick the processes and influences involved in mediating psychosocial well-being following childhood critical illness. Although not the focus of this study, more exploratory research is required to understand the experiences and well-being of the siblings of PIC survivors.

8.5.3 Concluding remarks

Undertaking research that utilises a reflexive and relational approach is an opportunity to learn about oneself and to '…engage in a transformatory process' (Holloway and Freshwater, 2007, p.45). This thesis has presented the narrative and journey of my own transformation from a neophyte to a more informed, experienced and independent researcher. Like the stories of the PIC survivors and their significant others, my journey was dynamic and has undulated. I have encountered and had to address a number of challenges while developing and undertaking this work. At the beginning of this journey, although I was an expert practitioner, I was a novice researcher and therefore constrained within the realms of what had been written, done and achieved before me. However, during this apprenticeship, I have developed insights and confidence that have inspired me to challenge myself as well as the status quo of inquiry. This has resulted in what I hope is a high quality piece of research that has provided a novel contribution to

the field in relation to understanding of the phenomenon. Furthermore, I have developed a wide repertoire of skills and knowledge that I hope will pave the way for my future academic and scholarly endeavours.

However, of equal importance and synonymous with my transition as a researcher, this experience has without doubt influenced, challenged and informed my identity and how I practise as a children's nurse. I have had the privilege to be invited into people's homes, their lives and their stories. I have been exposed to insights that have been evocative and provoked reflection of my own actions, standing, status and conduct as a professional, a researcher, and a social being. I, therefore, am more informed and my eyes are more open. Through the privilege of conducting this study, I have begun to understand what being a children's nurse is about. Furthermore, I comprehend how fundamental it is for nurses and other health professionals to challenge the status quo and provide platforms to liberate the unheard voices of our patients and their families in order to continually improve the quality, experience and outcomes of our care.

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Appendices

Appendix A – Interview schedule

Topic/theme	Prompt
Welcome and confirm willingness to proceed with visit	
Introduction/revisit the toolbox of methods	Drawing
	Photographs
	Artefacts
	Play
	Talking
Life story framework	Your story
	Your rules
About me now	Consider the self-portrait activity
	Age
	School
	Likes
	Dislikes
People in my life	Family
	Friends
	School
	Pets
My life:	Consider the time-lining activity past and future
-Before I was in critically ill	Remember
-When I was in critically ill	Think
-After I was in critically ill	Feel
-My future	Behave
	Do
Anything else?	

Appendix B – Visual tools to assist consenting process

The University of Nottingham

The **SCETCH** project

Retrospective review of PICU admission database and **screening** of eligible participants using study inclusion/exclusion criteria

Check eligible participant is **ALIVE** on Patient Admission System (PAS) and that postal address is correct.

Standardised study invitation letter with response slip, SAE and PIL/PIS sent to eligible participants via postal mail

Response slip returned?

Reminder letter sent from clinical team

Yes | No

Consented for contact details to be transferred to researchers?

No → No further contact

Yes

Researcher contacts respondents via telephone or email (as identified on response form)

Face to face information visit or telephone call conducted by researcher with eligible participant and parents/legal guardian to provide study information

Informed consent/assent obtained from both parents/guardian and child/adolescent?

No → No further contact

Yes

Initial data collection visit — *3 months* → Second data collection visit — *3 months* → Final data collection visit

Page 1 of 2

The SCETCH project – Study flowchart (Parent/guardian/child)
Final Version 2.0   Date 16.07.2012

Visit 1 (month 1)
(Duration: 1 hour)

Face to face visit with a researcher. At this visit the researcher will:
- Ask you and your child some questions about their illness and intensive care admission,
- Provide your child with art based equipment (pens, pencils, digital camera, paper) which your child will be able to use throughout their participation in the study,
- Talk to your child about telling their journey of recovery through drawings/paintings/play/photos and collecting this in a 'life story book',
- Discuss with your child about: what they can remember about being ill; what their life was like before they were ill; and what their life is like now,
- Ask your child about who they think is significant to them (for example parent, teacher, friend, or sibling) and whether they would like them to be invited to talk to the researchers.

1-3 months
(Optional) Your child continues to create their 'life story book'

Visit 2 (month 3)
(Duration: 1 hour)
Face to face visit with a researcher. At this visit the researcher will:
- Look with your child at their 'life story book' and discuss some of the content,
- With your child's permission take a copy of the content discussed,
- Ask your child some questions about how they feel and what their life is like now.

3-6 months
(Optional) Your child continues to create their 'life story book'

Visit 3 (month 6)
(Duration: 1 hour)
Face to face visit with a researcher. At this visit the researcher will:
- Look with your child at the 'life story book' and discuss some of the content,
- With your child's permission take a copy of the content discussed,
- Ask your child some questions about how they feel and what their life is like now,
- Provide an end of study debrief / Ask you and your child for feedback on being involved in the study,
- Ask you and your child for informed consent to be contacted to be invited to an event for the study findings to be disseminated

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Appendix C – Information visit schedule

The SCETCH project

Information visit schedule

1. Introductions
   a. Researcher – using my story
   b. Child/adolescent
   c. Other family members

2. Study overview using participant information sheet and visual flowchart

3. Look at Rachel's story and play with the tool box of methods

4. Answer any questions – Child/adolescent

5. Answer any questions – Parents/guardians/others present

6. Summary

7. Consent/assent/leave

Appendix D – Significant other's invitation letter and information sheets

The University of Nottingham

Faculty of Medicine and Health Sciences
School of Nursing, Midwifery and Physiotherapy
The SCETCH project team
Room B58, B-floor
The Medical School
Queen's Medical Centre
Nottingham, NG7 2HA

The SCETCH project

Survivors of childhood critical illness: Exploring long-term psychosocial well-being and needs

Date Printed here

Dear *Name of Significant other printed here*,

(Name of intensive care survivor participating in project) is taking part in a research project to explore and understand recovery of survivors of children's intensive care. We are particularly interested in what children, adolescents and young people's lives are like following discharge from intensive care. (Name of intensive care survivor participating in project) has identified you as a person that is important to them.

In order to find out more about (Name of intensive care survivor participating in project)'s recovery it is useful to gather information from other people. (Name of intensive care survivor participating in project) has asked us to approach you to speak with us for this project.

Before you and your child decide, we have included some information about the project that we would like you both to read carefully. Once you and your child have read this information, we would like you to consider whether you would be happy for your child to be involved in this project. Your child is under no obligation to participate in this project.

If you would like your child to participate or have any questions about the project then please contact Joseph Manning (Researcher) on:

    Tel: 0115 8230869
    Email: joseph.manning@nottingham.ac.uk

With kind regards,

The SCETCH project team

The SCETCH project – Significant other Parent guardian child Invitation letter
Draft1.1 Final version 1.0   Date: 16.05.2012

Faculty of Medicine and Health Sciences
School of Nursing, Midwifery and Physiotherapy
The SCETCH project team
Room B58, B-floor
The Medical School
Queen's Medical Centre
Nottingham, NG7 2HA

The SCETCH project

Survivors of childhood critical illness: Exploring long-term psychosocial well-being and needs

Date Printed here

Dear *Name of Significant other printed here*,

(Name of intensive care survivor participating in project) is taking part in a research project to explore and understand recovery of survivors of children's intensive care. We are particularly interested in what children, adolescents and young people's lives are like following discharge from intensive care. (Name of intensive care survivor participating in project) has identified you as a person that is important to them.

In order to find out more about (Name of intensive care survivor participating in project)'s recovery it is useful to gather information from other people. (Name of intensive care survivor participating in project) has asked us to approach you to speak with us for this project.

Before you decide we have included some information about the project that we would like you to read carefully. Once you have read this information, please consider whether you would be happy to be involved in this project. You are under no obligation to participate.

If you would like to participate or have any questions about the project then please contact Joseph Manning (Researcher) on:

Tel: 0115 8230869
Email: joseph.manning@nottingham.ac.uk

With kind regards,

The SCETCH project team

The SCETCH project – Significant other Adult Invitation letter
Final version 1.0   Date: 22.05.2012

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The University of Nottingham

Participant Information Sheet
(Significant other, Child/Adolescent)
(Final version 1.0: 22.05.2012)

The SCETCH project

Survivors of childhood critical illness:
Exploring long-term psychosocial well-being and needs

Hello,

My name is Joseph   and   my name is Sarah.

We need your help with a project we are doing.

We want to learn about what life is like for children after being very sick in hospital.

We would like you to take part.

What is a research project?

A research project is a way of learning about something.

Why is this project being done?

Children who are very sick have to go into hospital.

Most children get better (recover) and go home.

The nurses and doctors don't really know what happens to children like you after they leave hospital.

Why me?

You have been chosen by someone who is already taking part in this project. They were very sick and needed to go to hospital. They are now out of hospital. They have said you are important in their life.

Page 1 of 2

What will happen if I take part?

We will arrange to meet with you for about 1 hour. We will ask you some questions. You can choose whether you want to talk, draw or write to answer these questions and explain things. We will tape record the conversation. We will ask your permission to take a photo of any drawings/writing that you have done.

Do I have to take part?

No, it is completely up to you! Nobody will mind.

Are there any risks to taking part?

We want this project to be fun for you.

But some of the things you talk about might make you feel sad or upset. Your mum, dad, or grown up that looks after you will be there and we can stop our conversation if you want to.

We hope the information you give us will help other children who are very sick and leave hospital.

What shall I do now?

You need to think about if you want to take part or not.

Who can I ask about this?

Your mum, dad or the grown up who looks after you have been told about this project. If they are not sure, please let us know and we can tell you more.

If you would like to take part in this project or have any questions please contact Joseph on:

Telephone: 0115 8230869

Email: joseph.manning@nottingham.ac.uk

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Faculty of Medicine and Health Sciences
School of Nursing, Midwifery and Physiotherapy
The SCETCH project team
Room B58, B-floor
The Medical School
Queen's Medical Centre
Nottingham, NG7 2HA

Participant Information Sheet
(Significant other, Adult/Young Person)
(Final version 1.0: 22.05.2012)

The *SCETCH* project
Survivors of childhood critical illness:
Exploring long-term psychosocial well-being and needs

We would like to invite you to take part in our project. We want to learn about what life is like for children after they leave intensive care.

Before you decide we would like you to understand why the research is being done and what it involves.

We will go through the project information with you and answer any questions you have. Please ask us if there is anything that is not clear.

What is the purpose of the project?
In the United Kingdom 1 in 1000 children, adolescents and young people each year become critically ill and require admission to children's intensive care.

We know that admission to children's intensive care can be a very stressful and upsetting time for some children and their families. This can be caused by a number of things:

- Having invasive procedures (such as having a breathing tube inserted and being put on a breathing machine),
- Having medicines that have side effects such as hallucinations (bad dreams) and insomnia (not being able to sleep),
- Having a very sick child and not knowing what will happen.

However, doctors and nurses do not know what the long term recovery is like for young people who have left intensive care. We want to find out what life is like for children, adolescents and young people after they have left intensive care. This project will form part of a thesis for a higher degree (PhD).

Why have I been invited?
We are inviting you to take part in this project because you have been chosen by a child, adolescent or young person that is currently taking part. They have identified you as an important person in their life.

For each intensive care survivor that participates in this project, we are inviting up to 3 people that they identify as important to them to take part.

Do I have to take part?

It is up to you to decide whether you would like to take part. If you decide that you do not want to take part then you do not have to give a reason.

If you do decide to take part then we will ask you to sign a consent form. We will give you a copy of this form to keep.

What will happen if I take part?

We will arrange to meet with you. This can be at a convenient location for you. The visit will last about 1 hour and will involve asking you some questions relating to what you think about the nominating child's recovery.

This will involve questions relating to what you think the child was like before they were ill and what they are like now. We will record the interviews on a digital Dictaphone.

Expenses and payments

You will not be paid to participate in the project. However, any travel expenses incurred as a result of participation will be reimbursed.

What are the possible disadvantages and risks of taking part?

We hope that the project will be interesting and interactive.

Some of the topics that you may choose to discuss might be upsetting. If you become upset at any time during the interview we will ask you whether you want to stop the interview or have a break.

What are the possible benefits of taking part?

We cannot promise the project will help you but the information we get from this project may help our understanding of psychosocial wellbeing in children and families and their journey of recovery after critical illness. This could potentially help inform what information and services are provided to children and families who survive critical illness.

What happens when the research project stops?

At the end of the project you will be asked to feedback to the researchers about your experience of participation in this project.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher or ask to speak to the Chief Investigator. We will do our best to answer your questions (contact details are given at the end of this information sheet).

If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints via:

████████████████████████████████████

Will taking part in the project be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the project, some parts of your data collected for the project will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people

to check that the project is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the University of Nottingham will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for up to 12 months after the end of the project so that we are able to contact you about the findings of the project *and possible follow-up studies* (unless you advise us that you do not wish to be contacted).

You can ask us to remove this personal information later if you change your mind. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I do not want to carry on with the project?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without legal rights being affected. If you withdraw, then the information collected so far cannot be erased and this information may still be used by the project team.

Involvement of the General Practitioner/Family doctor (GP)
It is not necessary to inform your GP about your participation in this project.

What will happen to the results of the research project?
The results of this project will not be known until the last participant has received their final visit, which will be around May 2013. This project will form part of a thesis for a higher degree and will be reported in publications in journals and presented at various conferences.

None of the participants will be identified by name in any reporting of the findings. You will be invited to attend a dissemination event (Spring 2014) where you will be told of the findings.

Who is organising and funding the research?
This research is being organised by the University of Nottingham and is being jointly funded by the National Institute for Health Research (NIHR) and Nottingham University Hospitals NHS Trust as part of a Translational Research Fellowship.

Who has reviewed the project?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests.

This project has been reviewed and given favourable opinion by East Midlands Research Ethics Committee (Derby).

If you have any questions or would like to participate in this project please contact:

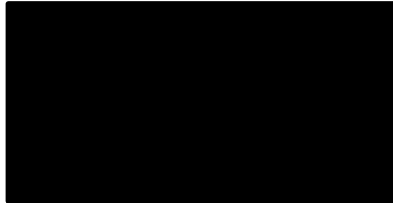**Joseph Manning (Researcher)**
Tel: 0115 82 30869
Email: Joseph.manning@nottingham.ac.uk

Dr Sarah Redsell (Chief Investigator)
Tel: 0115 82 30809
Email: Sarah.redsell@nottingham.ac.uk

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Appendix E – Invitation letter and participant information sheets

The University of Nottingham

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The **SCETCH** project

Survivors of childhood critical illness: Exploring long-term psychosocial well-being and needs

Date Printed here

Dear *Name of parent(s) and Child/adolescent printed here,*

My name is ███████████ and I am a Consultant Paediatric Intensivist (Children's Intensive Care doctor) at ███████████.

I am working on a project to understand the recovery of children, adolescents and young people who leave children's intensive care.

I would like you and your child to consider taking part in this project and have included some information for you to read together. Please assist your child to choose an information sheet they find easiest to understand.

Once you have both read the information, please let us know if you would like to talk to the researchers about taking part in this project. This can be done by completing the attached form and returning it in the stamped addressed envelope (provided).

If you have any questions that you would like answering before returning the attached form, please do not hesitate in contacting me or Joseph Manning (Researcher):

███████████████████████

Joseph Manning
Tel: 0115 8230869
joseph.manning@nottingham.ac.uk

With kind regards,

██████████████████████████

The University of Nottingham

The SCETCH project

RESPONSE FORM

Child's Name:	*Pre-printed here*

Parent(s)/Guardian(s) Name(s):	

Would you like to be contacted by the researchers to find out more about taking part in this project? (Please tick)	Yes ☐	No ☐

If you would like to be contacted please complete the information below:
(please leave blank if you do not want to be contacted)

Telephone (landline) number:	
Mobile Number:	
Email address:	
Home address:	

Preferred way to be contacted (please tick):	Telephone ☐	Mobile ☐	Email ☐

Thank you for taking the time to complete this form.
Please return via postal mail in the stamped addressed envelope provided.

Participant Information Sheet (Child)
(Final version 2.0: 17.07.2012)

The SCETCH project

Survivors of childhood critical illness:
Exploring long-term psychosocial well-being and needs

Hello,

My name is Joseph   and   my name is Sarah.

We need your help with a project we are doing.

We want to learn about what life is like for children after being very sick in hospital.

We would like you to take part.

What is a research project?

A research project is a way of learning about something.

Why is this project being done?

Children who are very sick have to go into hospital.

Most children get better (recover) and go home.

The nurses and doctors don't really know what happens to children like you after they leave hospital.

Why me?

Because you were very sick and needed to go to hospital.

What will happen if I take part?

We will meet with you to learn about what has happened.

You can tell your story by doing drawings, taking photos, painting, writing, doing poems, or talking. These will be collected in a 'story book' which you will keep.

Page 1 of 2

The SCETCH project – Participant Information Leaflet Child 6-10 years
Final Version 2.0   Date 17.07.2012
Readability: Words 533; Passive sentences 2%; Flesch Reading Ease 88.8; Flesch-Kincaid Grade level 3.5

If you are able, we will ask you to write your name on a sheet of paper called a consent form

This is to say that you are happy to tell us your story about after you left hospital.

We will ask you about the important people in your life.

So we can get to know more about you we would like to talk to people who are important to you (like your mum, dad, friends or teacher). We will ask your permission to talk to these people.

We will meet with you about 3 times to hear your story

We will tape record our talking. We will ask your permission to take a photo of your 'life story book'.

You will not be paid to take part in this project but you will be given a small gift of appreciation when the project ends.

Do I have to take part?

Not if you don't want to. Nobody will mind.

Will the project upset or help me?

We want this project to be fun for you.

But some of the things you remember might make you feel sad or upset. Your mum, dad, or grown up that looks after you will be there and we can stop our conversation if you want to.

We hope the information you give us will help other children who are very sick and leave hospital.

What shall I do now?

You need to think about if you want to join in or not.

Who can I ask about this?

Your mum, dad or the grown up who looks after you have been told about this project. If they are not sure, please let us know and we can tell you more.

If you want to ask us anything about this project please contact Joseph on:

Telephone: 0115 8230869

Email: joseph.manning@nottingham.ac.uk

The University of Nottingham

Participant Information Sheet (Adolescent)
(Final version 2.0: 17.07.2012)

The SCETCH project

Survivors of childhood critical illness:
Exploring long-term psychosocial well-being and needs

Hello,

My name is Joseph   and   my name is Sarah.

We need your help with a project we are doing.

We want to learn about what life is like for adolescents after being very sick in hospital.

We would like you to take part.

Why is this project being done?
Adolescents who are very sick are cared for on a special ward called children's intensive care.

Most adolescents get better (recover) and go home.

But nurses and doctors don't really know what happens to adolescents like you after they leave hospital.

Why me?
Because you have been very sick and needed to be cared for on children's intensive care.

What will happen to me in this project?

We would like to learn about your story since leaving intensive care by talking with you and asking you some questions.

You can choose to draw, take photos, do paintings, write, or do poems to tell your story.

These can be collected in a folder which you will keep. We will ask you to add to your folder when you want to.

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We will ask you to agree to be in this project by signing your name on a piece of paper called a consent form

This is to say that you are happy to tell us your story.

We will ask you about the important people in your life.

So we can get to know more about you we would like to talk to people who are important to you (like your mum, dad, friends or teacher). We will ask your permission to talk to these people.

We will meet with you about 3 times to hear your story

We will tape record our talking. We will ask your permission to take a photo of the work you have collected in your folder.

You will not be paid to take part in this project but you will be given a small gift of appreciation when the project ends.

Do I have to say yes to take part?

No, it is completely up to you! Nobody will mind.

If you decide to take part and then change your mind, that's OK as well. You can stop at any time and don't have to say why if you don't want to.

Are there any risks to taking part?

We want this project to be fun for you.

But some of the things you remember might make you feel sad or upset. Your parents or the grown up that looks after you will be there and we can stop our conversation if you want to.

We hope the information you give us will help other children who are very sick and leave hospital.

What shall I do now?

Now you know about the project you need to think about if you want to join in or not.

Who can I ask about this?

Your parent or the grown up who looks after you have been given lots of information. If they are not sure, please let us know and we can tell you more.

If you want to ask us anything about this project please contact Joseph on:

Telephone: 0115 8230869

Email: joseph.manning@nottingham.ac.uk

Page 2 of 2

The SCETCH project

The SCETCH project: Survivors of childhood critical illness: Exploring long-term psychosocial well-being and needs

Hello,

We would like you to take part in our project. We want to learn about what life is like for young people after they leave children's intensive care.

Before you decide we would like you to understand why we are doing this project and what it involves for you.

We will go through the project information with you and answer any questions you have. Please ask us if there is anything that is not clear.

What is the purpose of the project?

We know that admission to children's intensive care can be a very stressful and upsetting time for some young people and their families. This can be caused by a number of things:

- Having invasive procedures (such as having a breathing tube inserted and being put on a breathing machine),
- Having medicines that have side effects such as hallucinations (bad dreams) and insomnia (not being able to sleep),
- Being very sick and not knowing what is going to happen.

However, doctors and nurses do not know what the long term recovery is like for young people who have left intensive care. We want to find out what your life is like since you have left children's intensive care. This project will form part of a thesis for a higher degree (PhD).

Why have I been invited?

We are inviting you to take part in this project because you have been very sick and been admitted to children's intensive care in the past year.

We are inviting up to 20 children, adolescents and young people.

What will happen if I take part?

We would like to learn about your story since leaving intensive care by talking with you and asking you some questions. We will meet with you about 3 times to talk with you.

You can choose whether you want to draw, take photos, do paintings, write, or do poems to tell your story. These can be collected in a folder which you will keep. We will ask you to add to your folder when you want to.

So we can get to know more about you we would like to talk to people who are important to you (like your parents or friends). We will ask your permission to talk to these people.

We will tape record our conversations. We will ask your permission to take a photo of any work you have collected in your folder.

Do I have to take part?

It is up to you to decide whether you would like to take part. If you decide that you do not want to take part then you do not have to give a reason and any current or future treatment that you receive will not be affected.

If you do decide to take part then we will ask you to sign a consent form. We will give you a copy of this form to keep. You are free to withdraw consent at any time and without giving a reason. This will not affect your legal rights.

Expenses and payments

You will not be paid to take part in this project. However we will provide a small gift of appreciation on completion of the project.

Any travel expenses that you pay as a result of taking part will be reimbursed.

We will provide all equipment (such as pens, paper, and cameras) for the duration of the project.

What are the possible disadvantages and risks of taking part?

We hope that the project will be fun and interactive for you.

Some topics that you may choose to discuss with us might make you feel sad or upset. If you become upset at any time during a visit we will ask you whether you want to stop the conversation or have a break.

What are the possible benefits of taking part?

We cannot promise the project will help you but we hope this project will help our understanding of recovery following children's intensive care and other children and young people.

What happens when the research project stops?

We will ask you about your experience of taking part in this project.

If you use a study camera for the project we will collect this at the last visit. You can keep any unused art equipment (pens, pencils, paper). The 'life story' folder will remain your property.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher or ask to speak to the Chief Investigator. We will do our best to answer your questions (contact details are given at the end of this information sheet).

If you remain unhappy and wish to complain, you can do this by contacting NHS Complaints via:

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Will my taking part in the project be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the project, some parts of your data collected for the project will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the project is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the University of Nottingham will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen to my data?

Your personal data (address, telephone number) will be kept for 12 months after the end of the project so that we are able to contact you about the findings of the project *and possible follow-up studies* (unless you advise us that you do not wish to be contacted). You can ask us to remove this personal information later if you change your mind.

The research data recorded on the digital Dictaphone (voice recording device) will be removed and stored securely on a central computer at the University of Nottingham. Access to this audio data will be restricted to the study team. After the study ends this audio data will be securely archived at the University of Nottingham and retained for 7 years in accordance with University of Nottingham policy, after which it will be destroyed.

All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I do not want to carry on with the project?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, then the information collected up until that time cannot be erased but you can request for it to be excluded from the study. After the study has finished it will not be possible to exclude data from the analysis process.

Involvement of the General Practitioner/Family doctor (GP)

It is not necessary to inform your GP about your participation in this project. Unless requested by you, we will have no direct contact with your GP or any other health professionals.

What will happen to the results of the research project?

We will not know the results of this project until the last participant has received their final visit, which will be around May 2013.

This project will form part of a thesis for a higher degree and will be reported in publications in nursing/medical journals/presented at various conferences. None of the participants will be identified by name in any reporting of the findings.

You will be invited to attend an event (Spring 2014) where you will be told of the findings.

Who is organising and funding the research?

This research is being organised by the University of Nottingham.

It is funded by the National Institute for Health Research (NIHR) and Nottingham University Hospitals NHS Trust as part of a Translational Research Fellowship.

Who has reviewed the project?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests.

This project has been reviewed and given favourable opinion by East Midlands Research Ethics Committee (Derby).

If you have any questions or would like further information please contact:

Joseph Manning (Researcher)

Telephone: 0115 8230869

Email: joseph.manning@nottingham.ac.uk

Dr Sarah Redsell (Chief Investigator)

Telephone: 0115 82 30809

Email: Sarah.redsell@nottingham.ac.uk

Address: The SCETCH project team
Room B58, B-floor
School of Nursing, Midwifery and Physiotherapy
The Medical School
Queen's Medical Centre
Nottingham, NG7 2HA

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The University of Nottingham

Faculty of Medicine and Health Sciences
School of Nursing, Midwifery and Physiotherapy
The SCETCH project team
Room B58, B-floor
The Medical School
Queen's Medical Centre
Nottingham, NG7 2HA

Parent/Guardian Information Sheet
(Final version 2.0: 17.07.2012)

The *SCETCH* project
Survivors of childhood critical illness:
Exploring long-term psychosocial well-being and needs

We would like to invite your child to take part in our project. We want to learn about what life is like for children after they leave intensive care.

Before you decide we would like you and your child to understand why the research is being done and what it involves for you both.

We will go through the project information with you and answer any questions you have. Please ask us if there is anything that is not clear.

What is the purpose of the project?

In the United Kingdom 1 in 1000 children, adolescents and young people each year become critically ill and require admission to children's intensive care.

We know that admission to children's intensive care can be a very stressful and upsetting time for some children and their families. This can be caused by a number of things:

- Having invasive procedures (such as having a breathing tube inserted and being put on a breathing machine),
- Having medicines that have side effects such as hallucinations (bad dreams) and insomnia (not being able to sleep),
- Having a very sick child and not knowing what will happen.

However, doctors and nurses do not know what the long term recovery is like for children who have left intensive care. We want to find out what your child's life is like since you have left children's intensive care. This project will form part of a thesis for a higher degree (PhD).

Why has my child been invited?

We are inviting your child to take part in this project because:

- They are aged between 6 – 18 years,
- Have been very sick,
- Have been admitted to children's intensive care in the past year.

We are inviting up to 20 children, adolescents and young people.

Does my child have to take part?

No, it is up to you to decide whether or not you would like them to take part. If you decide that you do not want them to take part then you do not have to give a reason and any current or future treatment that your child receives will not be affected.

If you do decide for your child to take part then we will ask both you and your child to sign a consent form. We will give you a copy of this form to keep.

What will happen to my child if they take part?

Your child will be involved in the project for 6 months.

During this time he/she will have approximately 3 visits which will be about 3 months apart. However, if your child would like to have more or fewer visits then that is okay.

We would like to learn about your child's story since leaving intensive.

Your child can choose whether they want to draw, take photos, do paintings, write, or do poems to tell their story. These can be collected in a book or folder which they will keep. We will ask your child to add to their book/folder when they want to.

Each visit will last approximately one hour and be conducted by the same researcher (Joseph Manning). We will tape record the conversations. We will ask your child's permission to take a photo of any work they have collected in their folder.

The location of visits will be chosen by you and your child and will usually be within your home.

So we can get to know more about your child's life we would like to talk to people who are important to them (like parents, friends, teachers). We will ask your child's permission to talk to these people.

Expenses and payments

You or your child will not be paid to participate in the project. However we will provide a small gift of appreciation for your child on completion of the project. Any travel expenses that you pay as a result of taking part will be reimbursed. We will provide all equipment (such as pens, paper, and cameras) for the duration of the project.

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

We hope this project will be fun, interesting and interactive for your child.

Some of the topics that your child may choose to discuss with us might make them feel sad or upset. If your child becomes upset at any time during the visit we will ask you and your child whether you want to stop the visit or have a break.

What are the possible benefits of my child taking part?

We cannot promise the project will help you or your child.

We hope that the information we get will help our understanding of children's recovery after critical illness. This could help decide what information and services are needed for children and families who survive critical illness.

What happens when the research project stops?

We will ask you and your child to tell us about your experience of taking part in this project.

If you child has used a camera for the project we will collect this at the final visit.

Any unused art-based equipment (pens, pencils, paper) can be kept by your child. The life story book developed throughout the project will remain the property of your child.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher or ask to speak to the Chief Investigator. We will do our best to answer your questions (contact details are given at the end of this information sheet).

If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints via:

Will my child's taking part in the project be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If your child joins the project, some parts of his/her data collected for the project will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the project is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about your child during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about your child which leaves the University of Nottingham will have your child's name and address removed (anonymised) and a unique code will be used so that they cannot be recognised from it.

Although what your child says in the interview is confidential, should they disclose anything to us which we feel puts them or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

Your personal data (address, telephone number) will be kept for up to 12 months after the end of the project so that we are able to contact you about the findings of the project *and possible follow-up studies* (unless you advise us that you do not wish to be contacted). You can ask us to remove this personal information later if you change your mind.

The research data recorded on the digital Dictaphone (voice recording device) will be removed and stored securely on a central computer at the University of Nottingham. Access to this audio data will be restricted to the study team. After the study ends this audio data will be securely archived at the University of Nottingham and retained for 7 years in accordance with University of Nottingham policy, after which it will be destroyed.

All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

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

Your child's participation is voluntary and s/he is free to withdraw at any time, without giving any reason, and without their legal rights being affected. If your child withdraws, then the information collected up until that time cannot be erased but your child can request for it to be excluded from the study. After the study has finished it will not be possible to exclude data from the analysis process.

Involvement of the General Practitioner/Family doctor (GP)

It is not necessary to inform your child's GP about their participation in this project. Therefore, unless requested by you or your child, the research team will have no direct contact with your GP or any other health professionals.

What will happen to the results of the research project?

We will not know the results of this project until the last participant has received their final visit, which will be around May 2013.

This project will form part of a thesis for a higher degree and will be reported in publications in nursing/medical journals/presented at various conferences. None of the participants will be identified by name in any reporting of the findings.

You and your child will be invited to attend an event (Spring 2014) where you will be told of the findings.

Who is organising and funding the research?

This research is being organised by the University of Nottingham.

It is funded by the National Institute for Health Research (NIHR) and Nottingham University Hospitals NHS Trust as part of a Translational Research Fellowship.

Who has reviewed the project?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests.

This project has been reviewed and given favourable opinion by East Midlands Research Ethics Committee (Derby).

If you have any questions or would like further information please contact:

Joseph Manning (Researcher)
Tel: 0115 82 30869
Email:Joseph.manning@nottingham.ac.uk

Dr Sarah Redsell (Chief Investigator)
Tel: 0115 82 30809
Email: Sarah.redsell@nottingham.ac.uk

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Appendix F – Participant update

1- July 2013

- I finished the study visits with all the children and young people that were involved in the project.

- I was amazed by how much information we had collected. There was over 33 hours of talking and 427 photos and drawings.

2- August 2013 - March 2014

- I then had the task of organising all the information collected. I listened to the tape recordings of us talking and typed these up on the computer (these documents are called 'transcripts').

- I then did something called the 'analysis'. This involved reading these 'transcripts' over and over again. I also looked at your drawings and photos so I could understand more about your life and experiences.

- As you (and other people) had spent a lot of time helping with the project it was important that I took time to consider all the information.

- From this 'analysis' I produced a summary of your story and the stories of other people in your life. I then looked at how your story compared with other children and their families. Because there was a lot of information this took a long time.

3- February 2014

- I went to Sao Paulo in Brazil (where the football world cup was) to talk about our project with people who work at their university. We shared some ideas of how we could use what I had learnt from the SCETCH project to improve the care of other children and families.

- I also had two articles relating to the project printed in a kind of magazine called a 'journal'.

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4- April 2014

- I started a new job at Nottingham Children's Hospital as the 'clinical nursing research fellow/charge nurse'.

- It has a very long title but means I work as a senior nurse on children's intensive care as well as doing more research projects with other children and families.

5- May 2014

- I went to Istanbul in Turkey to the 2014 World Congress for Paediatric Intensive and Critical Care.

- I was selected to present some of the findings from the SCETCH project to children's intensive care doctors and nurses from around the world.

- I received an award for the presentation and got some very positive comments from the people there - which was fantastic!

6- Now until December 2014

- I am now writing up the SCETCH project into a very big book called a 'thesis'. Thankfully it will have some of your fantastic drawings and photographs in it to help break up the many words (about 90,000!).

- In October I will be going to Rotterdam in the Netherlands to meet with some of the doctors and nurses that care for children after they have been on intensive care. I hope to share the findings from our project and learn about the projects they are doing.

7- The future: Spring 2015

- In the spring I will be tested on the 'thesis' I have written (about the SCETCH project) by two nurses who work at universities. I will have to talk about the project; specifically what we did and why we did it. This is called a 'viva'.

- When we last met you may remember me talking to you about being invited to an event where we can talk about the findings from the SCETCH project. I would like to hold this event in the spring next year (2015) and also invite doctors, nurses and people who organise services for children (called commissioners) to come.

- I will send you an invitation to this next year, along with a summary of the project findings.

Contact Details:

Joseph Manning, Research Fellow

The SCETCH Project, School of Health Sciences,

Medical School, The University of Nottingham,

NG9 2HA

Email: Joseph.manning@nottingham.ac.uk

Telephone: 0115 8230869