

## **Title page**

### ***Full title***

Stories of survival: Children's narratives of psychosocial wellbeing following paediatric critical illness or injury

### ***Running head***

Children's stories of surviving critical illness

### ***Authors***

Joseph C. Manning

RN (Child), MNursSci (Hons), PhD

Clinical-Academic Senior Research Fellow in Children, Young People and Families Nursing

School of Health Sciences, Faculty of Medicine and Health Sciences, The University of Nottingham, Nottingham, UK; Children's and Families Research, Centre for Technology Enabled Health Research, Coventry University, Coventry, UK; Nottingham Children's Hospital and Neonatal Services, Nottingham University Hospitals NHS Trust, Nottingham, UK

Pippa Hemingway

RGN/RSCN, BSc (Hons), PhD,

Assistant Professor in Nursing Children and Young People/Professional Lead for Child

School of Health Sciences, Faculty of Medicine and Health Sciences, The University of Nottingham,  
Nottingham, UK

Sarah A. Redsell

RGN/RHV, BSc (Hons), PhD

Professor of Public Health

Faculty of Health, Social Care and Education, Anglia Ruskin University, Cambridge, UK

### ***Corresponding Author***

Dr Joseph C. Manning, School of Health Sciences, Room B42, B-floor, Queen's Medical Centre,  
Nottingham, NG7 2HA. Email: [joseph.manning@nottingham.ac.uk](mailto:joseph.manning@nottingham.ac.uk)

### ***Acknowledgements***

The children and young people that took the time to participate in this study and generously told their stories together with members of the study steering group who provided expert guidance.

### ***Conflict of interest***

No conflict of interest has been declared by the authors.

### ***Funding***

This research was conducted as part of JCMs' doctoral studies through a Translational Research Fellowship (2011-2014), which was co-funded by the National Institute for Health Research (NIHR) and Nottingham University Hospitals NHS trust.

## **Impact Statement**

- Approximately 1:1000 children, per annum, will experience a critical illness or injury, with the overwhelming majority surviving this event. Children who survive critical illness can experience a range of residual physical and psychosocial effects.
- This paper offers novel insights, through the stories of childhood survivors of critical illness/injury, into their long-term psychosocial wellbeing. This will generate awareness and impart understanding to clinical staff, managers, and service commissioners.
- Findings will prompt nurses and other health professionals to reflect on the relevance of the care and support delivered to children with critical illness, which may generate changes to their practice in supporting the child's journey following critical illness.

## **Abstract**

Survival from critical illness can expose children to an array of negative physical and psychological problems. While the perspective of parents and professionals have been well documented, there is limited understanding of how childhood critical care survivors make sense of their experiences in relation to psychosocial wellbeing. We aimed to explore long-term psychosocial wellbeing of childhood survivors of critical illness through their stories. A qualitative, exploratory study using serial in-depth interviews was employed. Nine children (aged 6-15 years) were recruited to the study six to 14 months post-discharge from a Paediatric Intensive Care Unit. Qualitative art-based methods were used with a responsive interviewing technique and data were analysed using Narrative Psychological Analysis. Four themes emerged: Disrupted lives and stories; survivors revealed uncertainties in their stories as they recalled their critical care event, Exposure to death and dying; talking about extreme physical vulnerability provoked anxieties, Mediating between different social worlds and identities; revealed the dynamic nature of survival, and Getting on with life; the prospective outlook survivors had on their existence despite newly manifesting adversities. Childhood survivors' stories identify challenges and adversities that are faced when attempting to readjust to life following critical illness that both enhance and impair psychosocial wellbeing.

**Keywords:** nurses, children, paediatric intensive care, survivors, narratives.

## Introduction

Childhood critical illness is caused by a wide variety of diseases and injuries but is characterised by a rapid loss of physiological reserve, which can result in significant morbidity or even death (Aylott, 2010). Due to advances in medicine, technology and care, mortality from critical illness is rare, with the majority of children admitted to the Paediatric Intensive Care Unit (PICU) being discharged alive (PICANet, 2016).

Surviving a critical illness or injury in childhood has been recognised as exposing the child (0-18 years old) to a range of disease-, treatment-, and environmental-related traumas or harms that can have an impact on physical, functional and mental health outcomes (Manning et al., 2016). However, despite high levels of survival, understanding children's outcomes and experiences following critical illness significantly lags behind medical advances (Dow et al., 2012). Existing research in the field has predominantly focused on uni-dimensional aspects of children's survival, by compartmentalising experience into either physical/functional (Ong et al., 2016), psychological (Rennick et al., 2011) or, in rare cases, social domains (Carnevale, 1997). This literature has identified that negative psychological impact, such as posttraumatic stress and mood changes, has been associated with survivors in the immediate to short term (Rennick and Rashotte, 2009; Colville, 2008). Furthermore, physical impairment and residual health problems manifest in the majority of survivors in both short and the longer term (Ong et al., 2016). However, only a limited number of studies have explored the phenomena of surviving childhood critical illness using a qualitative approach.

A systematic review and thematic synthesis of qualitative empirical studies (that included the following studies: Atkins et al., 2012; Wallace et al., 2007; Noyes, 2006), found that PICU survival can involve an array of adversities (Manning et al., 2014a). This can emanate from biographical disturbances and the misalignment between a focus on the survivor's 'normal' prior self and the reality of their potentially changed being. Subsequently, children are reported to experience transformation in relation to their physical status as well as identity in an attempt to overcome the

adversities that may be faced, such as disability, and chronic illness. For some, this involves acquiring and exploring other people's stories in an attempt to fill the missing picture of their time spend unconscious in PICU (Manning et al., 2014a).

However, published literature to date, fails to provide a contemporary, comprehensive and contextualised understanding of how PICU survivors construct and experience psychosocial wellbeing in the long-term (Rennick and Rashotte, 2009). Furthermore, the psychosocial trajectories of survivors following critical illness as reported by children themselves, and how they may change over time is unclear (Manning et al., 2014a). Therefore the aim of this study was to explore childhood critical care survivors, from England, describe and experience long-term psychosocial wellbeing through their stories.

## **Conceptual framework**

This study explored the narratives of child PICU survivors whose stories have been largely absent from previous literature in this field. A child-centred approach was therefore adopted which views children as knowledgeable, interactive, social beings that influence and are influenced by their social world (Freeman and Mathison, 2009; Christensen and Prout, 2002). In this study children were central, and involved in order to communicate their own views, experiences and needs (Carter and Ford, 2013). Children were recognised as individuals that viewed and interpreted the world and their experiences through their own personal belief systems (Crotty, 1998). In addition to recognising children as autonomous social actors, they were empowered to make decisions and choices about involvement, methods and conduct of the inquiry.

## **Study design**

This qualitative, exploratory study was underpinned by a narrative approach. A narrative approach congruent with the study's interpretivist-constructionist orientation was adopted that did not seek historical accuracy, but instead focused on the meanings constructed, and reconstructed, in participants' stories (Riessman, 2008; Polkinghorne, 1988). Serial in-depth interviews were used to understand how patient experiences and needs changed and were re-storied over time.

## **Materials and methods**

### ***Sample***

As outlined in the study protocol (Manning et al., 2014b), PICU survivors were recruited using purposive sampling and were identified through retrospective screening of a local PICU admission database. From 345 children, 32 were identified as eligible (using the inclusion/exclusion criteria, Table 1) and were invited to participate.

### ***Data collection***

Due to the diversity of the proposed sample (such as age, developmental level, and cognitive ability) 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 narrative (Rubin and Rubin, 2005).

In conjunction with responsive interviewing technique, child friendly art-based and visual approaches were also used to access experiences, views, and perceptions (Coad, 2007). Specifically, photo-elicitation (Croghan et al., 2008) and graphic-elicitation (Campbell et al., 2010; Jolley et al., 2004) techniques were used. These open-ended approaches acted as a platform to discuss, evoke

and explore participants' feelings, experiences, and stories (Hurworth, 2003). Each participant was given a digital camera and a box of art based equipment (including pencils, pens, and paper) to use and collect visual data during the study. This was collected during and outside of the interview encounters to provide opportunity for the child to construct their narrative at time points significant to them. Visual data collected included photographs, paintings, collage, drawings, writing and objects (such as toy or blanket).

Data were collected from October 2012 to July 2013 with a follow-up period of six to 20 months post-PICU discharge. All data collection visits were conducted by the lead author (JCM), a registered children's nurse and researcher, who had had no prior involvement in participants' clinical care. Data collection was predominantly conducted in participants' homes or at a location of their choice, often with a family member present. Interviews were audio recorded and individual photographs were taken of each visual piece produced. Survivors created a total of 1200 minutes of audio data and 412 images over 26 data collection visits. All but one survivor (who withdrew from study after first interview) completed a series of three interviews over the six month data collection phase.

### ***Ethical considerations***

National Health Service (NHS) Research Ethics Committee (REC) permission was obtained from East Midlands REC (12/EM/0230), England. As all participants were aged less than 16 years, parental informed consent was obtained. In addition, assent was gained from each child prior to participation in the study as well as at each encounter with the researcher. As advocated by Bray (2007), the assent process involved an interaction between the child and the primary researcher, where written, verbal and visual information was available and could be adapted to meet each child's individual needs to enable them to make an informed decision.

All visits were conducted with the parent present, or co-located in the house with parental permission. At the end of the study, a debrief was conducted to provide an opportunity for participants to reflect on their involvement. This also allowed primary researcher (JCM) 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.

Pseudonyms were used throughout the research and all identifiable information was redacted from the transcripts and visual images to maintain the participant anonymity.

### ***Data analysis***

Prolonged and in-depth analysis of the data was undertaken.

Narrative psychological analysis (McAdams, 1993; Crossley, 2000) was employed which is an holistic-content analytical approach. This form of analysis aligns to an interpretivist-constructionist standpoint as it recognises reality as a product of one's own creation; each individual sees, interprets, constructs, and re-stories the world and their experiences through personal belief systems (Crossley, 2000; Smith, 1995). Subsequently, this analytical approach attempts to gain insights into an individual's psychological and social worlds through understanding the content and complexity of meanings produced in interview situations (Crossley, 2000). As such audio data were transcribed verbatim (by JCM), with the visual images inserted into the transcript at the point of reference for Narrative Psychological Analysis to be undertaken.

The analytical process involved five stages (summarised in Table 2). Narrative Psychological Analysis was conducted by hand with each interview transcript. The visual data was not analysed in isolation, but instead as part of the interview encounter. Analysis focused on the story that accompanied the visual data and the meanings, experiences and insights that the child ascribed to it. A table was then populated with the imagery, codes/themes generated from the analysis and excerpts from the transcripts to provide transparency to the reader. From this table, the re-storied account was generated and written in full for each participant.

Initial analysis was conducted by JCM, with PH and SAR reviewing the audit trail and interpretations through discussions and written feedback.

### ***Rigour***

Strategies were employed to enhance the credibility, dependability, and trustworthiness of this study. All interviews were conducted and transcribed by JCM, a registered children's nurse and at the time also a doctoral student. It was perceived that continuity and prolonged engagement with the participants (over a six month period) enhanced parity and reciprocity during the encounters. In order to explore the situationality of the researcher, comprehensive reflective notes were taken with particular focus on relational and performative reflexivity.

### **Findings**

Nine survivors were recruited to participate in this study from a regional PICU located in England, UK. Participants included six boys and three girls (aged 6-15 years) with characteristics outlined in Table 3.

Analysis of survivor stories and life chapters resulted in four dominant themes 1) Disrupted lives and stories; 2) Exposure to death and dying; 3) Dealing with different social worlds and identities; and 4) Getting on with life, and 19 sub-themes (see Table 4).

#### ***Disrupted lives and stories***

Disorder and disturbances featured in all survivor stories. Disruptions manifested in both the content of survivors' stories, such as imagery from life-events and experiences, as well as their performance during the interviews. Across the majority of survivors, disturbances focused on pre-disposing deterioration, critical illness and hospitalisation experiences.

*“well this is what I heard cause I couldn't remember... he [Clare's Friend] 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 ...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..."*

*(Clare, 9 years old. Neuro-trauma)*

Confusion, doubts, and absences were 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. However, despite amnesia, distress surrounding their critical illness also disrupted 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, during and post critical illness. Hallucinations, their transitions of care, and observations of other children and patients all contributed to disturbed imagery.

*"It was quite scary and like there was this, when I was first in, when they took me to hospital, there was an old lady on the ward and she was screaming and screaming, it sounded horrible, and that scared me....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"*

*(Mark, 12 years old. Respiratory)*

Partially formed stories and memories emanated from confusion or unknown events, states or experiences 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 self-doubt. Some survivors appeared reluctant to tell their story and instead avoided engaging with the PICU event. However, for others being exposed to the telling of their story provoked negative emotions and adversity.

*“Mother: ... when you woke up you were upset because the nurses and the doctors wanted to put a mask over your face...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*

**[insert figure 1]**

*Andrew: [starts to cry]...Don’t, don’t...I don’t like you saying it [continuing to cry]”*

*(Andrew, 6 year old. Neurological)*

Building their story and life from an unknown states, experiences and events featured in the majority of survivor stories. Survivors 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 other survivors, it was evident that they rebuilt their life and story through telling someone else’s narrative. Other people’s stories were used to fill in the gaps of their own. However, despite being armed with these narratives, undertones of confusion and incomprehension manifested.

*“I was pretty happy with it [my life before being critically ill], and it just was like a nice life, and I can’t remember much more... I can’t remember any more much. 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, 7 years old. Neurological)*

### ***Thinking and talking about death and dying***

Thinking about death and dying featured in survivor's stories, situated around the critical care 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, sense-making processes, and dissociation.

*"...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. [I felt] sad yeah, but I don't really like thinking about that, that I nearly died yeah."*

*(Katherine, 15 years old. Sepsis)*

However, for other survivors (such as Sarah), despite provoking negative imagery, dissociation appeared challenging as it continued to occupy their thoughts and dreams.

*"Yes, because I just remembered how scared I was, and then I felt, I started to write it....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...Yeah, I saw one of them in my dream"*

### ***[insert Figure 2]***

*Big black worry hole...It made me feel really rubbish...I was worrying about if it would happen again, or if it would stop me from breathing and I'd have to get intubated again. I cried about it in the night...Because she died. Because I was poorly...My heart didn't work properly...And grandma gave me her heart, best thing that ever happened to me."*

*(Sarah, 8 years old. Respiratory)*

Contemplation of death of self and others was strongly evident in four of the nine stories with consideration of the death of close others used as platforms to reflect on their own existence. In some narratives this appears to enforce and exacerbate anxieties and fixations around their own mortality and the focus on the meta-physical beliefs. Obvious grief and anger are evident through the narrative content and performance and are associated with the death events and how the information is disclosed. Fears and anxieties were particularly prominent in stories where the critical illness was pivotal to disease diagnosis or a chronic health condition. For some survivors, the recall and engaging with their own mortality provoked fixations and worries. Their stories provided imagery of anxieties about their death and the potential of dying in the future.

*"...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."*

*(Mark, 12 years old. Respiratory)*

### ***Dealing with different social worlds and identities***

Dealing with different social worlds and identities was a theme that had high unity across survivors, with dynamic imagery of changing physical, psychological, emotional and social selves. Identities appeared to be defined and redefined during the survivors' 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 and chronic illness or residual disability.

Restrictions and social stigma were evident and 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.

*"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."*

*(Ollie, 7 years old. Neurological)*

Social stigma were apparent in a number of stories but particularly in the narratives of the older children. For some survivors' open disclosure of stigma from peers was used to redefine themselves and social identities in order to enhance their own social capital. Whereas other survivors' self and social identities were defined by their fear of being stigmatised due to their health or psychological status.

*"...I've talked with some doctors (about being on intensive care). I haven't talked with my friends about it, not much because they'll probably take the mick...They're just like that...They don't know much. They just, they know I've got asthma but they don't know how bad I am."*

*(Steve, 11 years old. Respiratory)*

Subsequently, some survivors actively concealed stories and identities from their social world in an attempt to protect themselves and others, such as their family. 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.

### ***Getting on with life***

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. However, survivors used their life experiences to inform future aspirations and goals. For some survivors, this appeared to inform a changed or transformed self, viewing their lives and selves from a different perspective.

*"I think I've changed a lot and I know how life works...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... 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... 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, 15 years old, Sepsis)*

However, for others, 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 their wish 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 wellbeing were professed by the majority. Emotional and psychological resilience was evident in the accounts of survivors, through imagery of determination and realignment of expectations being reported.

*"...well [I'm] 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 [explaining how Clare had injured herself] and then just like wow*



*...just looking back now it's just like I'm just happy that I can you know stay here and be okay...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... So it was a bit weird but you just get over it and carry on really."*

*(Clare, 9 years old. Neuro-trauma)*

Furthermore, some survivors' reported ambitions, aspirations and goals for their future lives that demonstrated their resilience and drive to overcome any adversity faced.

*"[insert figure 3] 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."*

*(Tim, 7 years old. Sepsis)*

## **Discussion**

Study findings identify that child PICU survivor stories of long-term psychosocial wellbeing are influenced, changed and determined by a multitude of factors. Although this study explored constructions over a longitudinal period, 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. Similarly in this study, findings do not 'fit' cleanly into any of the pre-defined theories that attempt to conceptualise the trajectory of survival. Instead, children's accounts were messy, chaotic and complex.

Disturbances in relation to stories of illness align with the concept of biographical disruption (Bury (1982) which exposes individuals to disruption in relation to their social and practical selves. Similar to the disruption identified from the findings of the systematic review and thematic synthesis

(Manning et al., 2014a), sources of confusion and uncertainty emanated from amnesia of the critical illness event. Colville et al. (2008) report that PICU survivors can experience a mixture of factual, delusional, fragmented, and absent memories at three months post critical illness. Although memory coherence varied amongst the survivors in our study, confused and uncertain states appeared residual up to 20 months post-PICU event. This 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 et al., 1997). However, irrespective of cause, amnesia appeared to impede some survivors in navigating their own biography and telling their story. The navigation out of a disrupted state was negotiated by survivors through avoiding or suppressing a desire to engage with associated imagery leading to detachment or disassociation. Extensive dissociation from traumatic, unknown and damaging experiences has been observed in connection with dissociative disorders as well as in PTSD symptoms (Kenardy et al., 2007).

In this study critical illness or injury exposed each survivor to potential death which provoked contemplation, sadness, and fear. However, this does not appear to align to the existing literature conducted with children who have experienced near-death experiences (NDE) (Morse 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). However, none of these themes appeared significant in the survivor stories. Instead the findings from this study indicate that it was contemplation on the critical illness event that appeared pivotal to survivors in recognising the severity of their condition and the subsequent vulnerability of their own existence. Exposure to their own potential death appeared to challenge not only their identity but also situationality within the world. Concepts of immortality were threatened, which appeared to provoke recognition of being different from peers. Although metaphysical contemplation has not been previously associated in the literature with PICU survivors, adult intensive care survivors have been reported to experience a 'spiritual awakening' (Papathanassoglou and Patiraki, 2003).

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 navigate this stigma through the use of 'passing strategies' in attempts to appear normal to peers (Carnevale, 2007). Passing strategies in this context refer to social concealment (avoidance) of the residual effects of the critical illness which featured through forward-facing stories and lives that avoided the imagery of adversity. This provoked disruption and mediation between public and family selves. Even in survivors where passing strategies were not an option due to obvious visual effects of critical illness such as hemiplegia, mediation was evident.

Prosperous constructions of psychological and social wellbeing emanated within and across all stories through positivity and hope. 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, hope and positivity associated with accounts of PICU survivors have been largely omitted from the existing literature. This is unsurprising as the dominant lens used to explore PICU 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 (Walsh, 2003; Taylor et al., 2000). In relation to children's stories, hope has been associated with accounts of home-ventilated children (Earle 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 highlights that children focus on the future in a manner that appears driven by the desire to resume normality.

### ***Strengths and limitations***

Key strengths of this study include: the longitudinal engagement in data collection and gaining different child perspectives of the phenomena of interest; and that children were actively involved in the development, design, and data collection approaches employed.

However, the study does have a number of limitations. 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, the sample lacked diversity in relation to ethnicity, potentially because of the absence of resources to translate information into languages other than English. Moreover, male PICU 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.

### **Conclusion and recommendations**

For the first time, this study has captured longitudinal stories from a heterogeneous group of nine child PICU survivors, six to 20 months post-discharge. Through maintaining the centrality of the inquiry on the survivors, novel understanding of long-term psychosocial wellbeing 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 group.

The PICU experience featured in all survivor stories. Congruent with the variance of outcomes reported in the existing literature, the significance of the PICU event in informing long-term psychosocial wellbeing varied considerably between survivors. However, survivor biographies appeared significant in governing wellbeing 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.

It is evident that further exploratory, longitudinal research is warranted in order to comprehensively map children's journeys of psychosocial well-being following critical illness/injury. This will allow for processes and influences involved in mediating psychosocial well-being to be identified. In turn, this will provide a platform for interventions to be developed, implemented and tested that can support and optimise survivors' psychosocial well-being in the longer-term following critical illness or injury.

## References

Atkins E, Colville G and John M. (2012) A 'biopsychosocial' model for recovery: A grounded theory study of families' journeys after a Paediatric Intensive Care Admission. *Intensive and Critical Care Nursing* 28(3): 133-140.

Aylott M. (2010) Caring for children with critical illness. In: Glasper EA and Richardson J (eds) *A Textbook of Children and Young People's Nursing* 2nd ed. Edinburgh: Elsevier, 691-718.

Bray L. (2007) Developing an activity to aid informed assent when interviewing children and young people. *Journal of Research in Nursing* 12(5): 447-457.

Bury M. (1982) Chronic illness as biographical disruption. *Sociology of Health & Illness* 4(2): 167-182.

Campbell C, Skovdal M, Mupambireyi Z, et al. (2010) Exploring children's stigmatisation of AIDS-affected children in Zimbabwe through drawings and stories. *Social Science & Medicine* 71(5): 975-985.

Carnevale FA. (1997) The experience of critically ill children: narratives of unmaking. *Intensive and Critical Care Nursing* 13(1): 49-52.

Carnevale FA. (2007) Revisiting Goffman's Stigma: the social experience of families with children requiring mechanical ventilation at home. *Journal of Child Health Care* 11(1): 7-18.

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

Christensen P and Prout A. (2002) Working with ethical symmetry in social research with children. *Childhood* 9(4): 477-497.

Coad J. (2007) Using art-based techniques in engaging children and young people in health care consultations and/or research. *Journal of Research in Nursing* 12: 487-497.

Colville G. (2008) The Psychologic Impact on Children of Admission to Intensive Care. *Pediatric Clinics of North America* 55(3): 605-616.

Colville G, Kerry S and Pierce C. (2008) Children's factual and delusional memories of intensive care. *American Journal of Respiratory Critical Care Medicine* 177(9): 976-982.

Croghan R, Griffin C, Hunter J, et al. (2008) Young People's Constructions of Self: Notes on the Use and Analysis of the Photo-Elicitation Methods. *International Journal of Social Research Methodology* 11(4): 345-356.

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

- Crotty M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process*, London: Sage.
- Dow B, Kenardy J, Long D, et al. (2012) Children's post-traumatic stress and the role of memory following admission to intensive care: A review. *Clinical Psychologist* 16(1): 1-14.
- Earle RJ, Rennick JE, Carnevale FA, et al. (2006) 'It's okay, it helps me to breathe': the experience of home ventilation from a child's perspective. *Journal of Child Health Care* 10(4): 270-282.
- Freeman M and Mathison S. (2009) *Researching Children's Experiences*, New York: The Guilford Press.
- Goffman E. (1963) *Stigma*, New Jersey: Prentice Hall.
- Hurworth R. (2003) Photo-interviewing for research. *Social Research Update (Spring)* 40: 1-4.
- Jolley RP, Fenn K and Jones L. (2004) The development of children's expressive drawing. *British Journal of Developmental Psychology* 22(4): 545-567.
- Kenardy J, Smith A, Spence SH, et al. (2007) Dissociation in children's trauma narratives: An exploratory investigation. *Journal of Anxiety Disorders* 21(3): 456-466.
- Lau U and van Niekerk A. (2011) Restorying the Self: An Exploration of Young Burn Survivors' Narratives of Resilience. *Qualitative Health Research* 21(9): 1165-1181.
- Manning JC, Hemingway P and Redsell SA. (2014a) Long-term psychosocial impact reported by childhood critical illness survivors: a systematic review. *Nursing in Critical Care* 19(3): 145-156.
- Manning JC, Hemingway P and Redsell SA. (2014b) 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).
- Manning JC, Redsell SA and Latour JM. (2016) Should out of sight mean out of mind? Challenging the role of paediatric intensive care in understanding and supporting children and families following childhood critical illness. *Nurs Crit Care* 21(5): 262-264.
- McAdams DP. (1993) *The stories we live by: Personal myths and the making of the self*: Guilford Press.
- Morse M, Castillo P, Vanecia D, et al. (1986) Childhood near-death experiences. *American Journal of Diseases in Children* 140(11): 1110-1114.
- Neimeyer RA. (2000) Narrative Disruptions in the Construction of Self. In: Neimeyer RA and Raskin JD (eds) *Constructions of Disorder: Meaning-making Frameworks for Psychotherapy*. London: American Psychological Association, 207-242.
- Noyes J. (2006) Health and quality of life of ventilator-dependent children. *Journal of Advanced Nursing* 56(4): 392-403.

Ong C, Lee JH, Leow MK, et al. (2016) Functional Outcomes and Physical Impairments in Pediatric Critical Care Survivors: A Scoping Review. *Pediatric Critical Care Medicine* 17(5): e247-e259.

Papathanassoglou EDE and Patiraki EI. (2003) Transformations of self: a phenomenological investigation into the lived experience of survivors of critical illness. *Nursing in Critical Care* 8(1): 13-21.

PICANet. (2016) *November 2016 Annual Report: Summary Report*, Leeds: Universities of Leeds and Leicester.

Polkinghorne DE. (1988) *Narrative knowing and the human sciences*, Albany: State University of New York Press.

Rennick JE, Johnston CC, Lambert SD, et al. (2011) Measuring psychological outcomes following pediatric intensive care unit hospitalization: Psychometric analysis of the Children's Critical Illness Impact Scale. *Pediatric Critical Care Medicine* 12(6): 635-642.

Rennick JE and Rashotte J. (2009) Psychological outcomes in children following pediatric intensive care unit hospitalization: a systematic review of the research. *Journal of Child Health Care* 13(2): 128-149.

Riessman CK. (2008) *Narrative Methods for the Human Sciences*, London: Sage Publications, Inc.

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

Smith JA. (1995) Semi-structured interviewing and qualitative analysis. In: Smith J, Hare R and Van Lagenhove L (eds) *Rethinking methods in psychology*. London: SAGE, 9-26.

Taylor SE, Kemeny ME, Reed GM, et al. (2000) Psychological resources, positive illusions, and health. *American Psychologist* 55(1): 99-109.

Wagner B, O'Hara D and Hammond J. (1997) Drugs for amnesia in the ICU. *American Journal of Critical Care* 6(3): 192-201.

Wallace M, Harcourt D and Rumsey N. (2007) Adjustment to appearance changes resulting from meningococcal septicaemia during adolescence: a qualitative study. *Developmental neurorehabilitation* 10(2): 125-132.

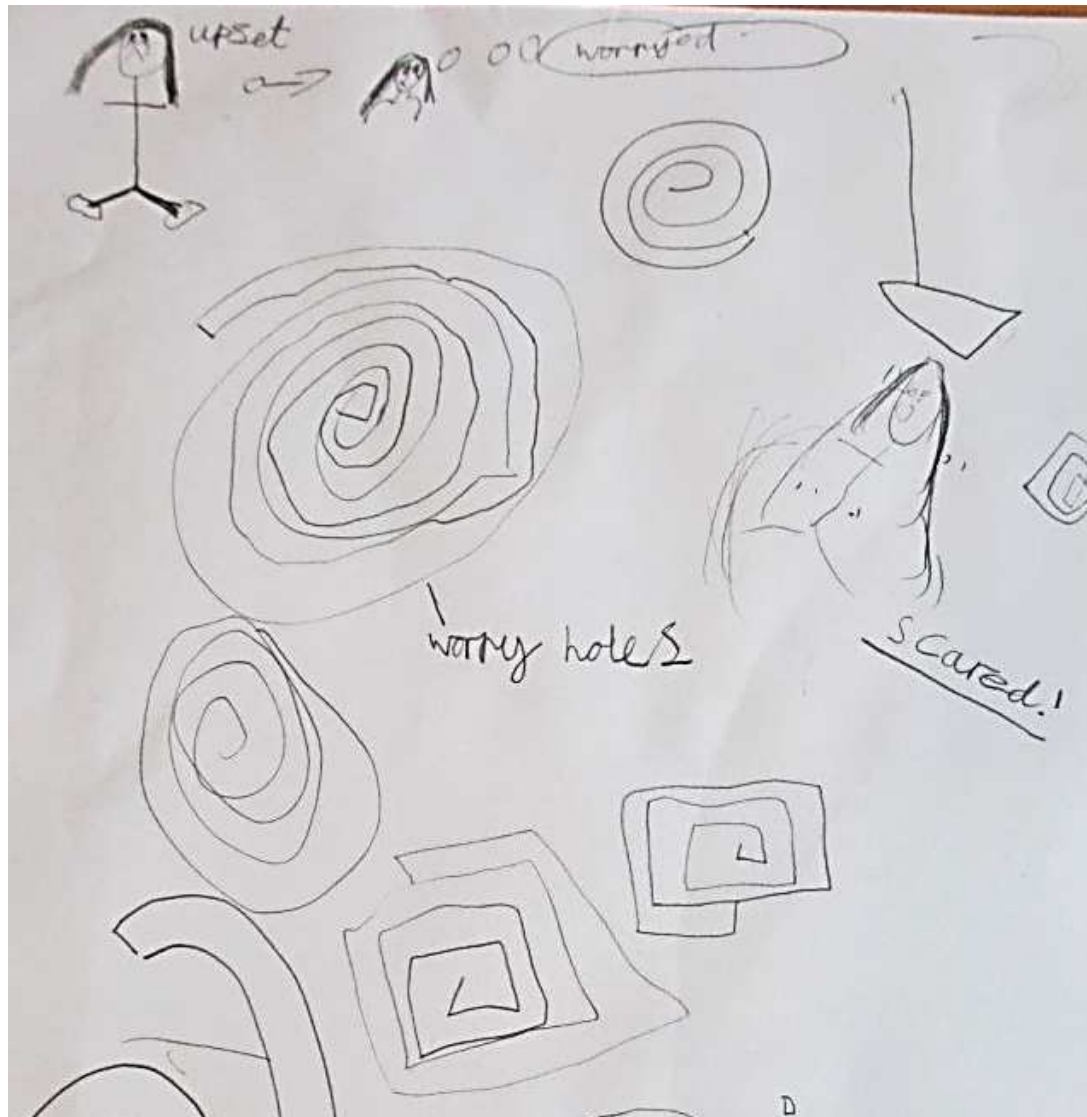
Walsh F. (2003) Family resilience: A framework for clinical practice *Family Process* 42(1): 1-18.



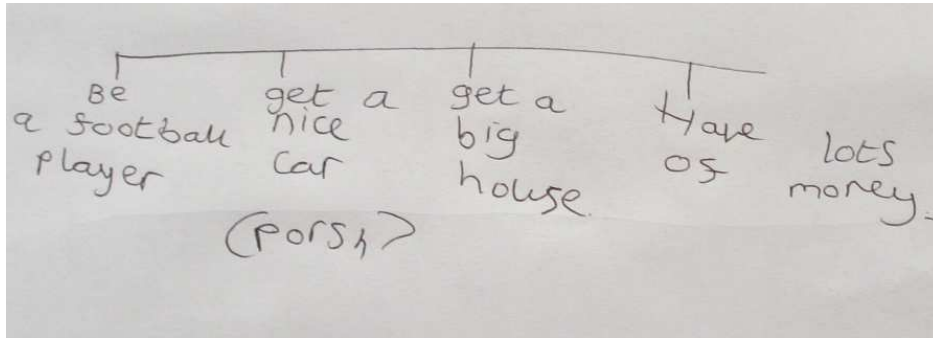
**Figure 1: Andrew's self-portrait**



Figure 2: Sarah's worry holes



**Figure 3: Tim's future**



**Table 1: Inclusion and exclusion criteria**

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Children aged between 6 - 18 years	PICU admission due to child protection issues
Survived emergency admission to PICU	On an active end of life care pathway
Invasively intubated and ventilated for at least 24 hours whilst on PICU	Non-English speaking
Three to 12 months since discharge from PICU	
Consents/assents to participate in study	

**Table 2: The stages of Narrative psychological analysis**

Stage	Description of processes
1. Reading and familiarising	<ul style="list-style-type: none"> <li>• 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)</li> <li>• This process is reported to allow the researcher to immerse himself in the content and take note of the atmosphere of the interview.</li> </ul>
2. Identifying important concepts to look for.	<ul style="list-style-type: none"> <li>• 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.</li> <li>• 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)</li> </ul>
3. Identifying ‘narrative tone’.	<ul style="list-style-type: none"> <li>• McAdams (1995), McAdams (1993) 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)</li> <li>• This step focuses on what made up the story (e.g. events) and how this is portrayed (e.g. optimism / sorrow / despair).</li> </ul>
4. Identifying ‘imagery’ and ‘themes’.	<ul style="list-style-type: none"> <li>• 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.</li> <li>• 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)</li> </ul>
5. Weaving it all together.	<ul style="list-style-type: none"> <li>• The final step is the ‘re-storying’ of the participant’s narrative.</li> </ul>

- |  |   |
|--|---|
|  | <ul style="list-style-type: none"><li>• This stage re-integrates the components of the holistic-content analysis of verbal and visual stories into a coherent story.</li><li>• 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).</li></ul> |
|--|---|

**Table 3: Study participant characteristics and data collection**

Survivor pseudonym	Gender	Age	Ethnicity	Household composition	Reason for PICU admission ICD-10 <sup>1</sup>	Time since critical illness at consent (months)	Time since critical illness at final data visit (months)	Underlying medical condition	Receipt of ongoing care	Number of data collection visits	Total audio data (minutes)	Total visual data (images)
Tim	Male	7	White British	Mother, Father and Sister	Sepsis	11	17	No	No	3	83	27
Sarah	Female	8	White British	Mother	Respiratory	6	12	No	Yes	3	189	44
James	Male	12	White British	Mother and Brother	Neurological	11	17	Yes	Yes	4	241	157
Clare	Female	9	White British	Mother, Father and two Sisters	Neuro-trauma	7	13	No	No	3	120	75
Steve	Male	11	White British	Mother and two Sisters	Respiratory	12	18	Yes	Yes	3	113	30

---

<sup>1</sup> ICD-10 (international classification of diseases 10) of disease that resulted in PICU admission as defined by the childhood survivor or their parent.

Katherine	Female	15	Black African	Mother and Brother	Sepsis	13	19	Yes	Yes	3	131	25
Andrew	Male	6	White British	Mother, Father and Brother	Neurological	6	-	Yes	Yes	1	53	6
Mark	Male	12	White British	Mother, Father and Brother	Respiratory	14	20	Yes	Yes	3	116	9
Ollie	Male	7	White British	Mother, Father and Brother	Neurological	11	17	No	Yes	3	154	39



**Table 4: Themes and sub-themes**

Theme	Sub-theme
1. Disrupted lives and stories	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