

“The world is losing this little girl”:
An exploration of hospital-based Children’s End of Life
Care through a Narrative Lens

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DECLARATION

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31st March 2021

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ABSTRACT

The death of a child is a profound and life-changing loss for all families. The majority of children continue to die in hospital due to the nature of the child's illness, the suddenness of their deterioration, and, at times, parental choice. The lack of research in this field in Ireland was one of the motivations for this study. Based in an acute children's hospital during a period of transition and amalgamation into a larger entity, the rationale for this study was to explore the experiences of families whose child was provided End of Life Care (EOLC) in the hospital and subsequently died, and the staff who cared for them.

Using a Narrative approach, the study is framed within a social constructionist perspective on bereavement, highlighting the belief that death occurs within a social context. 15 parents who had experienced the death of a child 6 months to two and a half years prior to being interviewed, were invited to share their experience through the use of a two part in-depth interview which took place in their own home or at the research site according to their wishes. In addition, 24 staff members at the research site were interviewed in focus groups using the same approach. Reflective Thematic Analysis was used as the method of analysis across all interviews, and narrative analysis was used to identify unique and enabling experiences from the interviews.

From the analysis of the parent interviews, three major themes emerged which reflected Turner's (1967) concept of "liminality" representing the changes that occur as families go through this key rite of passage. These themes convey parents' experiences of separating from their known world and entering into the complex and challenging world of EOLC. The focus groups for health care professions emphasised the complexities of the work in this area as well as the personal impact on staff. Further findings from a narrative reading of the data brought relationships between parents and staff to the fore. The role of staff in enabling moments of lasting significance for parents with their children is revealed. The findings from the study have been integrated into a "Map of Narrative Practice in Children's End of Life Care", highlighting the importance of relationship-based care, based on a shared sense of humanity around the tragic death of a child. This research emphasises the importance of communication and actions recognising the unique relationship between parents and their child and their deep emotional connection. By adopting a social constructionist and narrative approach, hospital-based children's EOLC can provide spontaneous opportunities to promote positive adjustment and endeavouring to minimise future complications in what is one of the most difficult bereavements.

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LIST OF ABBREVIATIONS

Abbreviation	Meaning
CPC	Children's Palliative Care
DNR	Do not resuscitate
DoHC	Department of Health and Children, Ireland
ED	Emergency Department
EOLC	End of Life Care
HCPs	Health care professions – including all members of the team caring for a child and their family
HSCPs	Health and Social Care Professional – refers to the grouping of professions who work within EOCL who provide therapeutic input including physiotherapy, occupational therapy, play therapy, chaplaincy etc. This term does not include medical or nursing staff
NICU	Neonatal Intensive Care Unit
PICU	Paediatric Intensive Care Unit
POD	Place of Death
SIDS/SUDI	Sudden Infant Death Syndrome/ Sudden Unexplained Death in Infancy – a child death for which there is no known medical cause

PROLOGUE

“The night before Ruairí passed away the nurses had arranged a bed in the ICU room to allow me to sleep with him. After a small amount of sleep, I woke to find my husband Rob and my Mam sitting in the room. A nurse, Jackie, then entered and asked if we had any breakfast? We all looked at one another not knowing what time it was or had we had any breakfast. The state of shock & disbelief of what was happening had left us all numb from reality.

Jackie offered to go and get us all tea & toast. Sometime later poor Jackie reappeared quite flustered explaining that she had to run all over the hospital to find a working toaster. It was so appreciated that a nurse had gone to so much trouble for us on what was going to be the worst day of our life.”

Mags, mother of Ruairí and member of Expert Advisory Group for this study.

CHAPTER 1: INTRODUCTION

The story in the prologue was written by a mother whose life was shattered a number of years ago when her 13 month old son died of meningitis. I was privileged to be part of the hospital team that took care of Ruairí and his family during his end of life care and bereavement. This mother is now part of the Expert Advisory Group for this study.

What Mags didn't include was the second part of this story which occurred six weeks later when I travelled to their home to do a post bereavement home visit. Such a visit is a routine part of bereavement follow-up provided by the hospital where I work. I went to see how they were doing, to try to provide some information to them to normalise their bereavement, and to see if they as parents had any questions about the end of life care provided to their son. As we talked in the kitchen beside Ruairí's highchair, the devastation caused by Ruairí's death was palpable. As I was leaving at the end of the visit, Mags produced a large parcel for me to bring back to the staff in the PICU. "It's a toaster and new coffee mugs for the staff room", she said. I obviously looked puzzled. She then told me the story that she wrote for the prologue of how, on the morning of what was to be the worst day of her life, when the life support machines were withdrawn and her son Ruairí died, the nurse on duty had to go all around the hospital to find a ward toaster that worked, to make Mags some toast, so that she could face the day. I still can't figure out which part of this story touches me more – the fact that, after such a devastating experience, Mags has the wherewithal to go out and buy the toaster so that I could bring it back to the hospital, or the determination of the nurse caring for the family that day that this mother would not face the death of her child without some food to strengthen and comfort her.

1.1 Introduction to the Study

For parents, the death of a child is a devastating experience, commonly referred to as the worst type of bereavement (Tan, Doherty, Barfield, & Brandon, 2012). It brings with it immense suffering for parents characterised by a multidimensional experience of pain, failure, despair and vulnerability (Kane and Primomo, 2001; Meert, Briller, Myers Schim, Thurston, & Kabel, 2009). A body of evidence now exists that provides the first clear evidence of the long term impact of such a death, affecting physical and mental health

for parents (Harper, O'Connor, Dickson, & O'Carroll, 2011; Harper, O'Connor, & O'Carroll 2014; Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Wijngaards-de Meij, Stroebe, Schut, Stroebe, van den Bout, van der Heijden, & Dijkstra, 2005), impacting their financial situation due to reduction of earnings and the long term reduced mortality, particularly for mothers (Li, Precht, Mortensen, & Olsen, 2003; Stebbins, Batrouney, & The Compassionate Friends of Australia, 2007).

For staff, the death of a child in a hospital can be an integral part of their everyday work or can be something that they experience very infrequently. It can occur within hours of meeting the child or can be a child they have known for many years, or sometimes even the child's whole lifetime. This work requires health care staff to ensure that they provide sensitive care in a complex and demanding area of medicine (de Cléty, Friedel, Verhagen, Lantos, & Carter, 2016; Papadatou, Bluebond-Langner & Goldman, 2011) while recognising the personal toll that this work can take (Clarke & Quin, 2007).

The site for this research is an acute children's hospital in Dublin, Ireland¹. The site hospital has a long history of providing health care to the local and national population for over 140 years. With services delivered by 1,500 staff, the hospital houses many national medical and surgical specialties, caring for 140,000 children per year from all over Ireland for both routine and highly complex care, including 49,000 children who present at the hospital's Emergency Department each year (Temple Street Children's University Hospital Annual report, 2018, p. 3). The site also has a strong connection to its local community and is physically located in the heart of the capital city, surrounded by an area of marked social deprivation.

This study takes place during one the of the largest national health care developments in Ireland. Following many years of protracted negotiations within health care and political circles, a "National Model of Care for Paediatric and Neonatal Healthcare Services" (Nicholson, Murphy, & Turner, 2017) was developed. This plan is based on the amalgamation of the three existing children's hospitals in Dublin (including site hospital) into a new legal entity called "Children's Health Ireland", which was legally enacted through the Children's Health Act 2018 (No 27 of 2018) in November 2018 and provided for the establishment of Children's Health Ireland ("CHI") on 1st January 2019 (New Children's Hospital, n.d.). While currently working on the existing three sites and following years of challenges with design and planning permissions, a new children's

¹ The term "Ireland" refers to the Republic of Ireland throughout the study.

hospital and two urgent care centres are currently being built to house this development. This new hospital will serve the children of Ireland with a national hub and spoke model of healthcare being fully implemented and centring on the new hospital currently being built and now scheduled for opening in 2024.

During the planning of this project, many patients, families and community groups were consulted to discuss and develop the physical site and the care to be provided there. To-date, no bereaved families have been consulted in relation to the project and this study aims to start the redressing of that deficit.

In Ireland, a child is defined by law as anyone under the age of 18 (Children First Act 2015). However, there is diversity in the definition and understanding of the age limit in which services are provided to children within a paediatric medical setting (Ehrich, Namazova-Baranova & Pettoello-Mantovani, 2016). Following a national review of the provision of paediatric medical services in Ireland, the “Review of Paediatric and Neonatology Services and Framework for Future Development” (Health Service Executive/Royal College of Physicians of Ireland, 2013) recommended the age of 16 as the limit for children attending paediatric services in Ireland. This recommendation is based on concerns about the challenges in providing services to older adolescents within a paediatric service and is now implemented within acute paediatric services in Ireland (Health Service Executive/Royal College of Physicians of Ireland, n.d.). As the site for this study is based within the paediatric medical services in Ireland, a child is defined as an individual from birth to age 16 for the purposes of this study.

1.2 Rationale for the Study

In this section the rationale for this study will be set out. This research sets out to explore the experience of parents and staff in children’s end of life care (“EOLC”) in order to provide a better understanding of children’s hospital-based deaths. Commencing with an outline of the key research questions, this section discusses the aims of the study and outlines the approach to be taken from a practitioner researcher perspective. The current debate in the literature about the appropriateness of “place of death” (“POD”) for children will be explored in order to set out the different viewpoints within the field. In addition, comment will be made on the current gaps in knowledge in relation to children’s EOLC and an outline of how this study might add to that knowledge will be provided.

1.2.1 Key Research Questions and Aims of the Study

It is critical in any research study to identify the broad questions which encompass the central purpose of the study (Creswell & Creswell, 2017). At the commencement of this study, the key research questions were set out:

1. What are the experiences of parents and staff during children's hospital-based EOLC?;

2. What lessons can be learned for future service development?

The **overall aims** of the study are to:

- Explore families' experiences of the hospital's role in supporting them through the EOLC and death of their child and invite them to reflect on what was most helpful and difficult for them in those experiences;

- Examine the experiences of staff providing support to families at EOLC and bereavement follow-up;

- Use these findings to inform and improve cross disciplinary practice in the children's EOLC;

- Bring the experience of bereaved families and staff "forward" into the planning and development process for psychosocial care of families at end of life and bereavement care at CHI through the development of a practice framework that will inform best practice in children's EOLC and bereavement.

This study has evolved during a critical time in the development of acute children's health services in Ireland. Taking into account the dearth of literature involving research with Irish families who have experienced EOLC of their child and the work that will be undertaken in the coming years to develop an amalgamated EOLC service within CHI, I believe that this study is timely. As well as informing planning and practice within an Irish

context, the study contributes to the international findings on parents' experience of EOLC and the important elements, for them, within that experience. In addition, by including the staff who care for families during this time within the study, further insights into this challenging area of children's medicine will be documented.

This study is, therefore, of significance to a number of different audiences.

- For *parents*, it provides an important voice in informing and supporting health care professionals to provide the best and most appropriate psychosocial care for those families they care for as they face the death of their child.
- For *health care professionals* working in a paediatric setting, this research will provide an insight into the experience of those families, hearing directly from parents, allowing staff to shape their service in a way that is most appropriate and helpful for families at some of the most difficult times of their life. Families experience the death of a child as "unnatural". Therefore, staff around them need to be highly sensitive to their needs, ensuring that parents are involved in the child's care, are informed at each step of the child's progress, are assured that the child has as comfortable and dignified a death as possible and are prepared for the child's death (Himmelstein, 2006; Meert et al., 2009; Robert, Zhukovsky, Mauricio, Gilmore, Morrison, & Palos, 2012; Steele, 2005).
- For *policy makers*, this research will provide evidence for the development of psychosocial supports for families facing the death of a child and how services might be adapted or developed to meet those needs.
- For the *social work profession*, this study will add to the very small field of research on the role of social work in children's palliative care. It will provide insights for social workers in applying their skills and knowledges to the area of children's EOLC (Wolfe, Grier, Klar, Levin, Ellenbogen, Salem-Schatz, ... Weeks, 2000), building relationships (Orlaff, 2011) and supporting families (Brody & Simmons, 2007).
- For the *empirical research audience*, this study will provide further evidence within this sensitive area of research.

The purpose of this research is to enhance the understanding of a parent's perspective on receiving psychosocial support from hospital staff during the time that a child in their family is being provided with EOLC in a hospital. Participants were also invited to explore

what types of support were most useful to them and identify any areas of support that might have been useful but were not offered. In addition, staff views on the provision of EOLC were also sought.

1.2.2. Being a Practitioner Researcher

This research is approached from the perspective of a “practitioner researcher”, as I am a social worker and social work manager working within the research site. This approach to research involves a curiosity about how research might support new ways of helping people (Uggerhøj & Wisti, 2020). Approaching this research from practitioner researcher perspective legitimates the “lived experience” of the practitioner in order to influence and improve future practice (Fook, 2002). Practitioner research recognises the unique position of a social worker at the confluence between service users and organisation and their ability to use research to influence service provision going forward (Shaw & Lunt, 2012). It involved recognising that the research takes place with the context of social work practice, and is, in turn, influenced by the social work context within which it takes place (Flynn & McDermott, 2016). For social workers, practitioner research is

“an inclusive approach to professional knowledge that is concerned with understanding the complexity of practice alongside the commitment to empower and address social justice issues, through practice.” (Salisbury Forum Group, 2008)

In order to successfully carry out such research however, it is critical that research practitioners recognise the ethical context within which they work (Mockler, 2014). When planning the research, power differentials should be recognised to ensure that participants are “free to participate, or not, without pressure” and are not in any way compromising their relationship with the researcher or the research site, while ensuring that anonymity and confidentiality are maintained (Flynn & McDermott, 2016, pg. 11). During the research, there are challenges for the researcher in acknowledging their own assumptions about the research field and how these assumptions might affect the development of knowledge (Lietz & Zayas, 2010; Rolls & Relf, 2006). The strong ethical structure that is integral to this research, supporting the research practitioner approach, will be detailed in Chapter 4. In order to embed and claim the ethical and reflexive stance within the research, the pronoun “I” will be used through the writing of this study (Gray, 2017).

This upholding of this stance throughout all phases of this research has been supported by an Expert Advisory Group. This group is made up of individuals chosen for their professional or personal experience in the field of children's EOLC. Together with my academic supervisor, this group comprises of five individuals from the clinical and academic fields of nursing, education and social work. The two remaining participants are "experience consultants", two bereaved mothers whose children died a number of years ago in the site hospital and who were happy to support the aims of the study by becoming involved to provide their unique perspective on the design and execution of the study. The Expert Advisory Group met together on three occasions during the study, with regular informal individual meetings or phone calls with members of the Group as needed throughout the study.

1.2.3. Death of a Child in a Hospital

While in the past the vast majority of children died in hospital, there is now a growing body of evidence highlighting the possibilities, preferences and benefits of a death at home, (Bluebond-Langner, Beecham, Candy, Langner, & Jones, 2013; Dussel, Kreicbergs, Hilden, Watterson, Moore, Turner, . . . Wolfe, 2009; Feudtner, Feinstein, Satchell, Zhao, & Kang, 2007; Higginson & Thompson, 2003). Indeed, within the palliative care field, home deaths are perceived as "good" deaths (Gao, Verne, Peacock, Stiller, Wells, Greenough & Higginson, 2016, p. 2), although clinical evidence for the general population of child deaths has not yet been documented. Some evidence exists that home deaths (for parents with children with cancer) can positively impact on their bereavement outcomes (Goodenough, Drew, Higgins, & Trethewie, 2004).

Any discussion of the location of death for a child must encompass the fact that, to-date, most research in this field is with families of children who died of cancer, which is an illness that medically allows for more predictability and planning (Dussel et al., 2009). Various studies have shown that, within the population of children who die as a result of cancer, figures as high as 52.2% (Higginson & Thompson, 2003), 62% (Dussel et al., 2009) and 77% (Vickers, Thompson, Collins, Childs, & Hain, 2007) were achieved for home-based deaths. However, a more recent population-wide review of cancer deaths in children in England over an extended period of ten years, suggested that an average rate of 40%, concluding that the rate of child deaths occurring had hardly changed for the past 20 years (Gao et al., 2016).

While death at home may be the choice for many, it is, unfortunately, not always an option (Dussel et al., 2009). Indeed, location of death is often not the greatest concern for families of dying children (Gao et al., 2016; Lövgren, Sejersen, & Kreicbergs, 2016). Not all parents express a preference for their child to die at home, even in oncology cases (Vickers et al., 2007). Figures for deaths at home outside of the field of oncology are scarce, with studies of the English population of child deaths in the periods 2013/14 and 2015/16 suggesting a rate of home-based expected deaths as low as 7% (Hartley, Renton, Clarkson, McKeating, Lyles, & Mayer, 2019). In Ireland, the team at Our Lady's Hospital for Sick Children, report a rate of 42% of hospital patients died at home in 2018 (Worrall, Gallagher, O'Reilly, Twomey, & Devins, 2019). Unpublished figures from the research site would align to this finding.

It is evident that, for many families, death at home is neither available as an option or the family's preference. As Bluebond-Langner et al. (2013) suggest, there is scant evidence that the purported preference of home deaths is appropriate as a general principle for child deaths. It is, therefore, expected that the development of excellent practice around children's hospital-based deaths is a critical part of the work of all children's hospitals going forward. Perhaps, as in adult palliative care fields (Ó Coimín, Prizeman, Korn, Donnelly, & Hynes, 2019), it now needs to be accepted that hospital-based child deaths are always going to be a part of the services to be provided to families at this very difficult time.

1.2.4. Limitations in Research in the Field of Children's EOLC

In examining the reasons for entering this field of study, several deficits have been identified within the literature in this area, which became part of the impetus for this study.

i. Research with Families Whose Child Died: As will be discussed in Chapter 2, there is now a strong body of work examining the need to support parents through the death of their child and afterwards (for example, Himmelstein, 2006; Meert et al., 2009; Morris, Gabert-Quillen, Friebert, Carst, & Delahanty, 2016; Price & Jones, 2015; Wender, 2012; Wood, Simpson, Barnes, & Hain, 2010). A growing body of research is evolving around the long-term impact for parents if these needs are not met (Harper et al., 2011; Lannen et al., 2008; Wijngaards-de Meij et al., 2005). Studies demonstrate a link between the support provided to families when a child is dying and its impact on a family's management of their child's death and bereavement

journey ahead (Tan et al., 2012), including the role that the hospital can play in this support (Morris et al., 2016).

While a body of research exists in this field, it has a number of significant limitations. Firstly, researchers have been reluctant to speak directly to bereaved parents (Dyregrov, 2004) and much work needs to be done to examine

“how [their] needs fit together, unfold over time, are shaped by and contribute to the making of a death context and influence parents’ bereavement experiences” (Meert et al., 2009, p, 713).

The inclusion of bereaved parents directly in research has now been shown to provide them with an opportunity to give something back to the staff who cared for their children (Robert et al., 2012) as well as a further opportunity to make meaning of their child’s death, a critical element of their bereavement journey (Moxley-Haegert, 2015).

In addition, the studies undertaken to-date have been predominantly with parents whose child has been dying from an illness that is more predictable (mainly cancer) (for example Monterosso & Kristjanson, 2008; Hinds, Oakes, Hicks, Powell, Srivastava, Spunt, . . . Furman, 2009) or where a child is born with a condition that is incompatible with life and dies as a neonate (for example Mulvihill & Walsh, 2014; Currie, Christian, Hinds, Robinson, Day, & Meneses, 2016b). Few studies have looked at the family perspective from the perspective of all causes of death (including deaths that result from a sudden illness or trauma).

ii. Research with Families Who Experience the Death of a Child in Ireland: When reviewing the literature published around the topic of children’s death in Ireland, studies centre around: review of the cause of children’s deaths; research with bereaved parents around services; and research with staff who work with families who experience the death of a child. The details of this body of research are outlined below. Studies highlight the deficits that exist in undertaking research with parents and staff where a child’s (other than a neonate) dies in a hospital. The identification of this gap in the literature added to the motivation to undertake this study.

Review of the Cause of Death: A number of articles exist that review the causes of child death in Ireland, including sudden infant death (McGarvey, McDonnell, Hamilton, O’Regan, & Matthews, 2006; Mehanni, Cullen, Kiberd, McDonnell, O’Regan, & Matthews

2000); cancer (Stack, Walsh, Comber, Ryan, & O'Lorcain, 2007); road traffic accidents (McGarvey, Hamilton, Donnelly, & Nicholson, 2019), epilepsy (Abdel-Mannan & Sutcliffe, 2020). Garrett (2014) outlined the development of a "death review process" for children who die while in contact with child protection services in Ireland. Helps, O'Donoghue, O'Byrne, Greene, & Leitao, (2020) reviewed the formal reports of children whose deaths were subject to a review because of health services mismanagement to examine the bereavement needs of those parents as documented in the reports.

Research with Bereaved Parents: A number of research studies explore the experience of parents who live through perinatal death in Ireland (Cullen, Coughlan, Casey, Power, & Brosnan, 2017; Mulvihill & Walsh, 2014; Nuzum, Meaney, & O'Donoghue, 2018). In relation to parents bereaved by the death of older children, three studies were found with Irish parents: Harmey, McDonnell, Synott, & O'Brien (1999) report the benefits to parents of bereavement support following the death of their child from sudden infant death; Jennings & Nicholl (2014) examined the experience of bereavement supports subsequent to their child's death as a result of a life limiting condition, demonstrating how mothers used their own internal resources, informal and formal supports during their bereavement; and Hanlon, Kiernan, & Guerin (2019) explored parent and staff experiences of a therapeutic bereavement camp which takes place in Ireland. In addition, a group of researchers based in Northern Ireland have explored the experience of parents caring for a child with a life-limiting conditions (Jordan, Price, & Prior, 2015; Price, Jordan, Prior, & Parkes, 2011; Price, Jordan, & Prior, 2013).

Research with Staff: A number of articles exist that deal with the experience of staff working with children with life limiting conditions including bereavement. Clarke & Quin (2007) examined the impact of this work from a multidisciplinary perspective. A number of studies review the practice of community nurses in Ireland who provide care for children with life limiting conditions and their families (Hill & Coyne, 2012; O'Brien & Duffy, 2010; Quinn, 2012; Quinn & Bailey, 2011). Nallen (2006) and Kalu, Coughlan, & Larkin (2018) examine the experience of midwives dealing with death and MacDermott & Keenan (2014) examine the experience of nurses caring for children with intellectual disability who die. A number of articles provide insight into the work of hospital chaplains supporting bereaved parents during and after a stillbirth (Nuzum, Meaney, & O'Donoghue, 2016; Nuzum, Meaney, O'Donoghue, & Jackson, 2017).

This summary of the literature which examines the experience within Ireland around the death of a child demonstrates the gaps that exist in research on this very specialised area of work, particularly studies that include parents describing their experience of EOLC and death of their child beyond pregnancy and early loss.

1.3. Death of a Child in Ireland

In this section of Chapter 1, a short review of the situation in relation to children's deaths in Ireland is included, in order to provide context to the study.

1.3.1. Statistics on Child Deaths in Ireland

With a population of 4,761,865 at the last population census in 2016 (Central Statistics Office, 2017), the Republic of Ireland experienced a total number of deaths of 31,765 in 2020 (Central Statistics Office, 2020), with an average life expectancy rate one year above the European Union average (OECD, 2019).

Centralised research on the figures for child deaths in Ireland is minimal. In order to examine the statistics on the prevalence of child death in Ireland, therefore, the information in this section has been collated from national reports and personal communication with the National Paediatric Mortality Register ("NPMR") which was recently tasked with the creation of a centralised register for child deaths in Ireland. As noted in Table 1 below, there were an average of 418 deaths per year of children age 0 – 18 in Ireland for the years 2012-2016 (NPMR, personal communication).

Compared with international figures, Ireland experiences a low number of child deaths, with an annual total average figure of 418 per year from 2012-2016. The following were figures provided from the NPMR for child deaths in Ireland by age for that period:

Year	Average Number of Child Deaths
Under 1	254
Age 1-4 years	44
Age 5-9 years	30
Age 10-14	29
Age 15-18	61
Total	418

Table 1: Average Number of Child Deaths by Age Per Year, Ireland 2012-2016 (Provided by the NPMR)

In keeping with international experience, the majority of children in Ireland die before their first birthday (Bryce, Boschi-Pinto, Shibuya, Black, & WHO Child Health Epidemiology Reference Group, 2005). In Ireland, for infants under one, there were 187 deaths registered in 2018, giving an infant mortality rate of 3.1 deaths per 1,000 live births (Central Statistics Office, 2019), reflecting a low level of infant death by international standards (MacDorman & Mathews, 2009). Figures show an average of 418 deaths per year from 2012-2016 of children up to 18 of which over 60% were under one (NPMR, personal communication, 2019).

In relation to the cause of those deaths, the figures available nationally for children living with life-limiting conditions is somewhat unclear with estimates of their prevalence nationally varying from 14.5 per 10,000 children (Irish Hospice Foundation/Laura Lynn 2013, p. 22) to 44 per 10,000 children (Ling, O'Reilly, Balfe, Quinn, & Devins, 2015, p. 93) providing a possible range of 1,300 to 3,800 children nationally falling within this definition. Figures for death rates for children with life-limiting conditions are not available.

Other causes of child deaths include sudden or unidentified illness (for example meningitis, SUDI), road traffic accidents, other accidents, (for example farm accidents, accidents in the home) and suicide. A number of public safety measures, such as a public information campaign on the cause of SIDS deaths and a public road safety campaign has resulted in a serious decrease in these causes of deaths (McGarvey et al., 2019). However, the rate of suicide among young people remains of serious concern (McMahon, O'Regan, Corcoran, Arensman, Cannon, Williamson, & Keeley, 2017). While the records for child suicide are not collated in Ireland, recent reports show annual suicide rates for individuals ages 15-24 of 17 per 100,000 (male) and 4.8 per 100,000

(female) in the period 2007-2018 (National Suicide Research Foundation n.d.). During this study, two child suicides were identified among the deaths taking place in the site hospital. While experiencing a low death rate for children in Ireland, for each family involved this experience is life changing and its impact is felt well beyond the period of ill-health and death.

1.3.2. Place of Death for a Child in Ireland

In reviewing the place of death for children in Ireland, the figures below provide detailed analysis of where child deaths took place during the years 2013-2017 in Ireland (NPMR, personal communication, 2019). As can be seen, the largest group of children died in hospital, following sequentially by maternity hospitals, at home or hospice. No data is available about location of death for a small number of children. This chart supports the argument made earlier that, because of the nature of their deaths, a large proportion of child deaths (up to half) will continue to take place within a paediatric hospital setting. In addition, the maternity hospitals will continue to care for children who die as a result of pregnancy complications or in the period immediately after birth.

Year	Hospitals	Maternity Hospitals	Hospice	At Home	Elsewhere
2013	204 (55%)	96 (25.9%)	5 (1.4%)	56 (15.1)	10 (2.6%)
2014	218 (58.8%)	101 (26.8%)	1 (0.3%)	46 (12.2%)	10 (1.9%)
2015	173 (52.7%)	95 (29.0%)	1 (0.3%)	48 (14.6%)	9 (3.4%)
2016	157 (50.5%)	99 (31.8%)	2 (0.6%)	47 (15.1%)	4 (2.0%)
2017	142 (48%)	98 (33.1%)	1 (0.3%)	47 (15.9%)	7 (2.7%)

Table 2: Place of Child Death in Ireland 2013-2017 (Information from NPMR, Personal Communication, 2019)

1.3.3. Care of the Dying Child in Ireland

Ireland has a long tradition of recognising the needs of the dying (Kealy & Tracey, 2005; May, Hynes, McCallion, Payne, Larkin, & McCarron, 2014; O'Brien & Clarke, 2005) with religious and voluntary organisations providing hospice care since the 19th Century (Department of Health and Children, 2001). The development of palliative care for children arose out of the national review of palliative care needs published by the

Department of Health and Children (“DoHC”) in 2001 (O’Reilly, 2005), which clearly recognised the unique and special needs of children and their families. A further assessment of palliative care needs (DoHC 2005) and national policy (DoHC 2009) for children were published. Within these documents, there is clear recognition that the needs of children are similar to those of adults but with some critical differences.

In order to promote a national approach to the development of Children’s Palliative Care (“CPC”), the DoHC’s 2005 report highlighted the four critical elements of CPC including:

- *Inclusiveness* (including the child, raising awareness among health care professionals, and skills training for parents);
- *partnership* (including the voice of all stakeholders, particularly the child);
- *comprehensiveness* (providing care on a holistic basis); and
- *flexibility* (with a care plan that is designed for each child and family according to their needs across time) (DoHC, 2005, p. 12).

In keeping with the recommendations of the DoHC’s 2005 report, a national model of support services for children with life-limiting conditions and their families was developed. Comprising of the appointment of a small number of medical consultants and a network of locally based nurses specialised in working with children with life limiting conditions, a country wide network of services is currently being provided, in tandem with the existing community-based health care services (Jordan & Fullerton, 2016). The implementation of those policies has been progressed, spearheaded by voluntary organisations such as the Irish Hospice Foundation and Laura Lynn Children’s Hospice. While some specialist CPC posts have been established (Ryan, Connolly, Charnley, Ainscough, Crinion, Hayden, Keegan, Larkin, Lynch, McEvoy, & McQuillan, 2014), palliative care nationally continues to be provided from a generalist, rather than a specialist perspective, with most staff providing this care among their other health care duties (Kane, Daveson, Ryan, McQuillan, Higginson, & Murtagh, 2015). Further work is required to fully implement all of the recommendations of the Irish Government’s 2005 and 2009 reports (Kelly, 2018).

1.4. Introduction to Children’s Palliative and End-of-Life Care

This section provides an introduction to the area of CPC. Growing from the field of adult palliative care (Craft & Killen, 2007; Lenton, Goldman, Eaton & Southall, 2006), specialist care for children and their families at end of life is an emerging area of study (Knapp, Woodworth, Wright, Downing, Drake, Fowler-Kerry, . . . Marston, 2011). First defined in 1997 (Wood et al., 2010), and developed in the UK (Dangel, 2002), CPC encompasses the medical, nursing, and psychosocial care of a child with a life limiting condition and their families throughout the trajectory of their illness, EOLC and bereavement (European Association of Palliative Care, 2007; Liben et al., 2008; Price & McFarlane, 2009). In Ireland, the need for services in CPC have been recognised at national level in the policy documents developed by the Irish Government (DoHC, 2005; DoHC, 2009) but the implementation of all of the recommendations contained in those policy documents remain in their infancy (Jordan & Fullerton, 2016).

The term ‘Palliative’ derives from the latin word ‘*palliare*’ meaning to cloak (Wolfe, Hinds & Sourkes, 2011, p. 4), providing the individual and their family with a holistic approach to care when they are experiencing a life-threatening illness (Weaver, Heinze, Kelly, Wiener, Casey, Bell, . . . Hinds, 2015). CPC combines a scientific and humanistic approach to the care of the child and their family (Kane & Primomo, 2001), promoting quality of life and choice about the child’s care (Feudtner et al., 2013; Himelstein, 2006; Liben et al., 2008). While a number of definitions of CPC exist (Craft & Kileen, 2007; World Health Organisation, 2018), the most widely-used definition is that created by the Association for Children with life threatening or terminal conditions and their families (“ACT²”) and the Royal College of Paediatrics and Child Health in the UK (“RCPCH”) (Harrop & Edwards, 2013; Wood et al., 2010):

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.” (Together for Short Lives, 2018, p. 9)

² In 2011, several voluntary organisations caring for children with life limiting conditions in the UK, including ACT, amalgamated together to form Together for Short Lives.

Clear categories of illness have been identified to allow for the inclusion of a broad spectrum of children with serious illness (see ACT definitions in Appendix 1). In CPC, the emphasis of care for children is the experiential, rather than medical, promoting the concept of "hope for the best and prepare for the rest" (Remke & Schermer, 2012, p. 295). With the different trajectory of each child's illness, and the different strategies adopted by each family to manage the illness (Steele, 2005), the pathway to CPC and how that journey manifests itself can be different for each child.

The definition above belies the inherent complexity of CPC. Lack of clarity exists among both families and health care professionals in relation to the concept of CPC (Clarke and Quin, 2007; Monterosso, Kristjanson, Aoun & Phillips, 2007) and confusion about terms such as "life-limiting" can serve to exclude a broader group of children from CPC services (Cadell, Kennedy & Hemsworth, 2012; Wolfe, Hammel, Edwards, Duncan, Comeau, Breyer, . . . Dussel, 2011). In Ireland, this confusion is hampered by lack of a national database on children who may benefit from CPC (Ling et al., 2015).

The unique aspects of CPC can also cause challenges including:

a) *child development theories* required a different approach from adult palliative care that takes into account the child's physical and psychological development (Lenton et al., 2006; Wolfe et al., 2011; Wiener, McConnell, Latella & Ludi, 2013);

b) *the child's place and complex dynamic within their family* is a critical aspect of care in CPC, mirroring the history of that child within the family, as well as the spoken and unspoken expectations that that family has for their child (Craft & Kileen, 2007; Kane & Primomo, 2001; Monterosso et al., 2007; O'Reilly, 2005; Payne, 2008);

c) *the timing of the introduction of CPC* depends on the readiness of both the child and the parents to become involved in those conversations (O'Reilly, 2005; Price and McFarlene, 2009);

d) *variation in availability of services depending on geographical location*: Due to its relatively early stage of development, the provision of CPC teams is not universal and can cause a wide variety of service provision depending on geography (Craft & Kileen, 2007; Price & McFarlene, 2009);

e) *different legislative frameworks* can result in children being treated differently in different legislative areas, at times with opposing views between parents and medical teams (Joseph, 2018; Wilkinson & Savulescu, 2018) and

f) *Lack of specific cultural approach in CPC* can mean that a family's religious or spiritual beliefs are incongruous with the philosophy of CPC (Liben et al. 2008; Wiener et al., 2013).

Indeed, the concept of CPC is only helpful if families, rather than just professionals, embrace the approach and use the services to enhance their lives during the time of their child's illness (Monterosso & Kristjanson, 2008; Wiener et al., 2013). In addition, children who die of sudden causes such as accidents or suicide are not included within the ACT categories, excluding them and their families from this very important area of care.

1.4.1 Children's End of Life Care

The recognition and provision of EOLC for children is a complex and challenging area for children, their families and for the staff who care for them (Longden, 2011). In their work to promote understanding of CPC, the International Children's Palliative Care Network provided the following definition:

"End of life care ... focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition, this includes care during and around the time of death – and immediately afterwards. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support." (International Children's Palliative Care Network, 2017)

Traditionally, EOLC is provided within a certain medical prognosis of death (Wolfe et al., 2011). With children, however, it is essential to recognise that anticipating and accepting the possibility of death of a child is an experience that "throws the universe into a state of disequilibrium and calls for an entirely different level of coping for all family members, especially parents and siblings" (Dickens, 2014, p. 119) resulting in gaps between staff recognition and parental acknowledgement of the need for EOLC (Wolfe et al., 2000). Studies have shown that how families deal with the possibility of EOLC can depend on

the nature and ethology of the child's illness (Dussel et al., 2009; Higginson & Thompson, 2003). For children with cancer, for example, where the medical pathway is more predictable, a higher acceptance of and planning for a child's death has been found (Klopfenstein, Hutchison, Clark, Young & Ruymann, 2001; Wolfe et al., 2008). In contrast, a much lower level of planning is found when children die from a range of other causes (McCallum, Byrne & Bruera, 2000). Such findings demonstrate the complexity of the decision-making process for parents in relation to an end of life approach with the result that EOLC is often only provided between the period of parents' realisation that the child cannot survive and their death (Von Lutzau, Otto, Hechler, Metzinger, Wolfe, & Zernikow, 2012).

Equally, health care providers can struggle with deciding when EOLC is appropriate (Akpınar, Senses & Aydinet, 2009; Dombrecht, Piette, Deliens, Cools, Chambaere, Goossens, . . . Cohen, 2020). In some situations, CPC includes the concept of "parallel planning", with the child being actively treated for any medical issues while at the same time taking an active approach to quality of life issues (Beecham, Oostendorp, Crocker, Kelly, Dinsdale, Hemsley, . . . Bluebond-Langner, 2017; Wolff et al., 2011). However, parallel planning can be fraught with difficulties with concerns that introducing end of life planning can cause conflict between the family and the clinical team (Sidgwick, Fraser, Fortune & McCulloch, 2019).

1.5. Outline of the Thesis

This chapter provided background context to the undertaking of this study of the experience of parents at EOLC of their child and the experiences of the staff who care for them. The death of a child is recognised as a most difficult bereavement, with the potential for long term physical and psychological impact for parents. This is also a challenging area of paediatric medicine for staff involved in the care of dying children. An overview of child deaths in Ireland was provided as well in addition to a summary of the approach to the provision of children's palliative care. The chapter also outlined the rationale for the study, highlighting the gaps in research carried out in Ireland.

Chapter 2 outlines the sociological and philosophical framework that supports this study. The concept of a social constructionist approach to death and dying will be introduced and its appropriateness in providing a more inclusive perspective on the role of staff who

care for families facing bereavement will be discussed. The concept of “liminality” will be explored and an introduction to its applicability within the field of medicine provided. In addition, Chapter 2 will introduce the overarching narrative approach adapted for this study, as well as the concepts from narrative psychotherapeutic practice that will support the discussion of the findings from this study and provide a framework for construction of the “Map of Narrative Practice in Children’s EOLC” described in the Chapter 7.

Chapter 3 contains a Literature Review highlighting the current research in terms of the experiences of both parents and staff in the field of children’s EOLC. The psychological and emotional experiences of parents are explored emphasising the immediate and long-term impact of this experience on parents. The complexity of this area of work for staff is examined, outlining the need for close interdisciplinary working, excellent communication and inclusiveness of parents in the decision making around their child’s care. In addition, the emotional impact of the work on staff is explored.

Chapter 4 will describe the methodological approach to this study. It will explore the social constructionist epistemology which underpins this research and supports the narrative approach adopted in this study. This chapter will also explain the ethical framework created to ensure that this study, in what is understood to be as a sensitive area of research, is safe for all of the participants. The selection and recruitment of participants will be discussed and demographic information on all parent participants and their children who died is included. Demographic information for the participating staff is also included. The chapter goes on to provide a background to the narrative approach to the analysis of the data and details the reflexive thematic analysis approach used to analyse the findings from the interviews.

Chapter 5 will report on the findings from the parent interviews using the three major themes that were developed from the thematic analysis: 1) Entering the liminal space of end of life care; 2) “Being” in transition; and 3) Emerging from Liminality. Each theme is explored in depth to highlight the main findings of the parent interviews.

Chapter 6 will contain the finding from the interviews with staff. These are split into two sections:

- a) health care professionals (including doctors, nurses and health and social care professionals) with its overarching theme of “Implementing End-of-Life Care while Recognising its Challenges”; and
- b) social workers with its major theme of “Enabling Families to Find their own Path”.

Each section highlights the major themes that emerged from data collected through focus groups with health care professionals and social workers respectively.

Chapter 7 will provide a discussion chapter exploring the findings of the research through a narrative lens which examines in detail how parents felt well supported by staff through a shared sense of humanity around the tragic death of their child. Applying concepts from narrative practice, the use of reassuring and enabling conversations, and recognition by staff of the importance of definitional ceremonies and remembering conversations is explored. A description of the “Map of Narrative Practice in Children’s End-of-Life Care” developed from the research findings is included in this Chapter.

Chapter 8 draws together the work and the findings from the research, highlighting the key findings around the view of the death of a child as a liminal experience, the importance of relationship-based care, within that liminal context and the work by staff to create collaborative conversations with families in order to enable them to have minimal regrets during their child’s EOLC.

1.6. Conclusion

This first chapter has provided the background and context to the study that I undertook to explore the experiences of parents and staff at children’s EOLC. The chapter introduces the complex world of children’s EOLC. The limited demographic data available about child deaths and their causes was explored to provide an Irish context to the study. In addition, the rationale for undertaking this research in a sensitive field of study was outlined, as well as the purposes which it will serve.

CHAPTER 2: SOCIOLOGICAL AND PHILOSOPHICAL FRAMEWORK

“We are the tellers of tales. We each seek to provide our scattered and often confusing experiences with a sense of coherence by arranging the episodes of our lives into stories” (McAdams, 1993, p. 11)

I have chosen to open this chapter with the above quote from McAdams (1993) as it encompasses, in many ways, what I as a researcher endeavoured to achieve within this study. As described in Chapter 1, one of the motivations for this study was a sense of injustice that bereaved families' opinions had not been sought in the planning and development of CHI, a hospital that will, when it is open, provide services to the largest number of dying children and bereaved families in Ireland. No-one was invited to tell this story - it remained a story not yet told, which needed to be collected and retold in a way that can influence the services provided in the future. With one of the key tenets of research in the social work field being to address social justice (Epstein, Fisher, Julkunen, Uggerhoj, Austin, & Sim, 2015), the idea of this research was born. In early iterations of the title for this study, the concept of the “gathering of the voices” of families who had had this experience was included in the title of the study, reflecting my belief that an approach that centred those voices and their stories. Listening to children's and family's stories within paediatric medicine provides one of the key ways that those working in that area can gain a deeper understanding of the patient and the family (Robinson, 2002). With the narrative approach to research espoused the idea that “personal stories thus often operate as bids for representation and power from the disenfranchised” (Squire, 2013, p. 62), it became the chosen approach. Indeed, as Devisch, Van Heule, Deveugele, Nola, Civaner, & Pype (2017) suggest that researchers need to begin to reflect on the idea that by listening to the “narrative” of individual's involvement in tragic events, recognising their lived experience and providing help to them in the process. “Since the willingness and ability to listen to the narratives of others are in themselves a direct expression of caring, narrativity and narrative skills are inseparable from caring” (Devisch et al., 2017, pg. 259). The authors go on to suggest that through that process of listening or bearing witness within the research process, we can offer a new perspective on the participants' experience, helping them to achieve a deeper understanding of their lives.

While a detailed discussion of the narrative approach to this research will follow later in the chapter, I will first outline the sociological, philosophical and anthropological ideas that have added to the framework that underpins this study. Any research framework provides a theoretical “blueprint” from which to frame the study, a guide on which the study is built and supported (Osanloo & Grant, 2016). A theoretical framework such as this is “a structure that summarizes concepts and theories”, developed from published research to provide a theoretical background for the planning and undertaking of the study as well as the analysis and interpretation of the findings from the research data (Osanloo & Grant, 2016; Kivunja, 2018, p. 46). In developing a framework that provides a context to this study, I sought to anchor the study into a context that would highlight ways of understanding the experience of the death of a child, as McAdams (1993) suggested, to provide a “sense of coherence” to an experience that is life-altering (Price & Jones, 2015). As I have described in previous chapters, this is an infrequent, yet devastating experience for a family, one that is not well understood. I have sought to bring together from the worlds of sociology, philosophy and anthropology, a framework that can surround the discussion within this study. In addition, this framework serves to bring this world of children’s EOLC out from being perceived as a very private and personal experience, to an experience that occurs within a social and anthropological context. My purpose in doing this is to demystify this experience, to explore it in a way that will resonate with a wider audience, so that a broader understanding of this life-changing experience can be generated.

In this chapter, the broad theories from the field of sociology, philosophy and anthropology supporting this study are discussed, while the research paradigm and the methods employed to execute the study will be discussed in Chapter 4. This chapter discusses the social constructionist approach to death and bereavement and introduces concepts from anthropology that will influence the analysis and understanding of the findings of this research. The overarching narrative framework for this study is discussed and concepts from narrative psychotherapeutic practice are introduced that will support the discussion of the findings from this study and provide a framework for construction of the “Map of Narrative Practice in Children’s EOLC” described in chapter 7.

2.1. Social Constructionist Approach to Death and Dying

In the process of reviewing the literature on children’s EOLC, I was struck by the dominance of a medical discourse. As a social worker, I was interested to explore a wider

framework within the fields of sociology and anthropology that might contribute to the creation of a wider, socially based description and understanding of that experience. Western society's perspective on death has fundamentally changed in the past 100 years (Katz, 2000). Walter (1996) classified society's approaches to death as traditional, modern and post-modern. The traditional approach saw death as a natural part of life, with all families experiencing death regularly at home and within their community (Aries, 2000[1981]). Kearl (1995) suggests that this experience of viewing death as a daily occurrence facilitated the development of a recognition of the limits of human life. "Theirs were generations of character, the products of pain and tragedy" (Kearl, 1995, p. 6). A modern approach sees death as the responsibility of medicine and hospitals (Corr, 2015; Mellor & Shilling, 1993), resulting in it being hidden away. This presents huge challenges to the medical and allied professionals, who view death as the "enemy" (Gold, 2005 [1977]), because it may have been avoided or is the result of failure of the medical system (Melvin & Lukeman, 2000). The death of a child, in particular, is seen as unnatural and rare, and one of the most difficult bereavements (Muckaden, Dighe, Balaji, Dhiliwal, Tilve, Jadhav, & Goswami, 2011).

In a post-modern approach to death, a strong palliative care movement supports an approach which has as broad a possible choice that suits the individual involved (Van Doorslaer & Keegan, 2001). Such a palliative approach for children who have life limiting conditions is well developed (Feudtner, Womer, Augustin, Remke, Wolfe, Friebert, & Weissman, 2013; Himmelstein, 2006; Liben, Papadatou, & Wolfe, 2008). Where there is the opportunity for forward planning, deaths frequently occur as the family choose (Bluebond-Langner et al., 2013; Feudtner et al., 2007). However, in an acute paediatric setting, the implementation of such concepts remains in its infancy, and is compounded by the circumstances of the child's death (Liben et al., 2008). Ironically, the evolution of this post-modern approach to a "good death" (Gao et al., 2016) can result in socially prescribed circumstances for such a death, relegating deaths that do not fit this set of criteria to the category of "bad" deaths (Hart, Sainsbury, & Short, 1998). This is particularly true when children die in a hospital, with an erroneous assumption that this experience is somehow lesser for the child and family as it did not occur at home (Bluebond-Langner et al., 2013).

Parallel to this change in society's perception of death has been the move, particularly within the fields of counselling and psychology, to internalise the bereavement process (Hayslip & Page, 2013; Monroe, Oliviere, & Payne, 2011), leaving the individual

responsible for their own bereavement resolution. Neimeyer, Klass & Dennis (2014) raise a concern that such an approach suggest that the resolution of the “pathology” resides within the competency and responsibility of the individual arguing that such an approach could further individual’s distress and not recognise the potential for the bereaved to find meaning through their social interactions and social world. Payne (2009) expresses concern about a growing perspective within the palliative care movement that death is a problem that requires fixing, resulting in the pathologizing of suffering and grieving and the implicit feelings of “suffering and impotence, the feeling of life gone wrong” (Devisch et al., 2017, p. 260). Neimeyer et al. (2014) raise the concern that

“in the terminology of narrative therapy ..., individuals are subjected to and sometimes subjugated by a dominant narrative of grief, which constructs their identity as bereaved people, and which regulates their proper performance of their role as mourners in ways that may correspond or clash with their personal predilections” (pg 490).

The dominant narrative that sites the resolution of grief within the individual is, therefore, unhelpful at best and complicating the mourner’s journey at worst. Neimeyer et al. (2014) present this concern more forcibly. “Simply stated, society polices bereavement. It controls and instructs the bereaved how to think, feel and behave” (pg. 490).

The use of a social constructionist approach helps broaden understanding of the experience of individuals and families during the dying process and afterwards. At its core, social constructionism offers the perspective that the world is understood through the social interactions among people (Burr & Dick, 2017; Gergen, 2004). Such a view can provide a broader approach to bereavement, one that is less onerous for the individual, by focussing on the death as a “social process, conditioned by social and cultural factors” allowing for the development of an approach to death and dying that is based on concepts of the social context of the dying and bereaved (Payne, 2009, p. 515). Within this perspective, Neimeyer et al. (2014) suggest that

“... meaning is as commonly negotiated between people as within them, as the bereaved seek validation of their accounts of the significance of the loss from friends, family, co-workers, and sometimes bereavement professionals” (pg. 487).

The acknowledgement of the role of social groups as active influencers in the individual's development of knowledge and coping within their bereavement (Drisko, 2013b) allows for bereavement to become a community rather than individual concern. While this perspective could challenge an institution such as a hospital, the adaptation of a social constructionist perspective would allow it to take a strong position in supporting families to face a death, helping them to learn about and develop resilience. While a relatively new concept within acute health care, Neimeyer et al.'s (2014) invitation to explore this perspective in our work and research serves as encouragement to adopt this position during this research process.

In order to expand the idea of death and bereavement as socially constructed, ideas from social anthropology are now explored. These constructs view the experience of loss through death as a "Rite of Passage", with the bereaved individual going through a confused and complex period of "liminality".

2.2. Experience of Death and Bereavement as Rites of Passage

In order to review the theories of death and dying from an anthropological perspective, the concept of "liminality" was explored. This section of the chapter will examine the main tenants of liminality, tracing its history from the field of social anthropology, and discussing some of the most pertinent concepts in its current development.

2.2.1. Introduction to the Concept of Liminality

The term "limin" has its origin in the Latin language and refers to the concept of a "threshold" (Rallison & Raffin-Bouchal, 2013). With the origins of its use in the world of anthropology, it refers to "biological and social transitions and the ritual processes that accompany them." (Braude, 2012, p. 108). Arthur van Gennep first used the term in 1903 in his book "Rites of Passage". An anthropologist, van Gennep undertook ethnographic studies examining the rituals surrounding life transitions in minority populations around the world. From this work, he brought together the overall schéma or patterns which "accompany a passage from one situation to another or from one cosmic or social world to another" which he called "rites of passage" (Van Gennep, 1903/1960, p. 10).

Rather than distinct phases of the transitional experience, the patterns suggested within Van Gennep's Rite of Passage have also been described as "clusters of behaviour" This ritualization of death allowed (Braude, 2012) or "movement" (Jordan et al., 2015), highlighting the individual nature of the experience of these Rites of Passage. Van Gennep (1903/1960) found that these behaviours could be grouped into three broad schemes: preliminal rites (rites of separation), liminal rites (rites of transition) and postliminal rites (rites of incorporation) (p. 11).

1. Preliminal Rites (Separation): This cluster of behaviours signified the individual's preparation to separate from their previous identity or status in society. It is a complete separation from the known world (Eaton & Hornborg, 2009). The clearest example of this in Van Gennep's (1903/1960) work were the structured rituals that young tribe members undertook in their passage to adulthood, often involving a physical distancing from the rest of the tribe. This physical separation allowed the individual to prepare for the stripping away of their previous identity as a child and begin to prepare for the tribal rituals that signified their entrance into adulthood.

2. Liminal Rites (Rites of Transition): For Van Gennep, the Rites of Transition were the most significant of these processes as they signified and structured the transitional experience of the individual. The "limen" or threshold functions as a boundary or marker for the experience of space or time. In addition, it functions as a psychological marker signifying the commencement of the transformation of the individual to commence "any event of becoming" which are marked by "delicate and volatile tipping or turning points." (Stenner, Greco, & Motzkau, 2017, p. 3). According to Turner (2012), "This threshold time is unfamiliar to the novice, experienced in a strange land with - as it were - long avenues revealing not-yet-understood wonders." (p. 168).

3. Postliminal Rites (Rites of Incorporation): Van Gennep (1903/1960) suggested the process of regrouping or aggregation during the part of the process in which the individual undergoes a reformulation of their sense of being. During this process, the individual takes on the attributes of their new being, re-entering the world in their changed shape.

Van Gennep did not believe that these schemes were time related or fixed, and that each part of the transition, in each situation could take on a different meaning for the individuals experiencing it. There were however commonalities in these transitional

periods which signified the changes that took place during the process: “There is a dying of the old; that which has passed away, and there is waiting for the new to arrive.” (Rallison & Raffin-Bouchal, 2013, p. 197), an “overturning of everyday norms and concepts.” (Braude, 2012, p. 108).

Van Gennep’s findings lay unrecognised for many years, perhaps because his work was not translated into English until the 1960 (Thomassen, 2012) or perhaps because his academic colleagues in France, where he resided, did not recognise Van Gennep’s work due to his position as a freelance writer, rather than an academic (Hockey, 2002). However, in the mid- 60s, fellow anthropologist, Victor Turner rediscovered Van Gennep’s work and applied it to his study of Ndembu tribal rituals. In his work, Turner (1967) elaborated on the description of this liminal phase, outlining it as a stage of ambiguity, where the individual “passes through a realm that has few or none of the attributes of the past or coming state” (p. 94). Turner stresses how the individual experiences a world that is unknown to them, without the assurances of the world that was familiar to them and not yet with the knowledge of the world that was to come. He further discouraged the notion of the different aspect of liminality as being phases or stages suggesting a period of space or time which is an “interstructural situation” (Turner, 1967, p. 93). However, this is not a passive experience but one which facilitates the generation of this new identity, “a psychosocial intentionality of being” (Andrews & Roberts, 2012, p. 1)

2.2.2. The Concept of Space and Time in Liminality

Central to Van Gennep’s concept of Liminality is the notion that it represents time and space (Madge & O’Connor, 2005). Liminality occupies a space – either physical or psychological that surrounds and situates the liminal experience. The concept of time too, is critical to understanding the liminal experience. Anthropologist, Edmund Leach (1976), developed the concept of liminality by describing the individual’s liminal experience as progressing through the “totality of his (her) socially recognised existence” (p. 34). Leach (1976) goes on to say that “the spatial and temporal markers which actually serve as boundaries are themselves abnormal, timeless, ambiguous, at the edge, sacred” (Leach, 1976, p. 35).

*i. **Temporality:*** In examining further the concept of temporality, the concepts developed by philosopher, Paul Ricoeur will be used in this study. Ricoeur

(1984) in his first volume of *Time and Narrative*, described how humans experience time from two perspectives: firstly, the *linear process* of time, as we experience the movement of time in chronological order and in logical sequencing and secondly, the concept of the *phenomenon of time*, the understanding that is gained of the concept of the past, the present and the future, and the meaning of our experience from each of those contexts. For Ricoeur, the human experience is a combination of both of those meanings of time, and we cannot understand our experience without taking both concepts into account. “Time has no being since the future is not yet, the past is no longer, and the present does not remain.” (Ricoeur, 1984, p. 7). Ricoeur’s two concepts of time (i.e., chronological and phenomenological time) will be used within this study to allow the examination of experience with different lenses that facilitate the understanding of experience from different perspectives.

ii. Spatiality: In addition to temporality, the concept of space is a central feature of liminality, with space being defined both physical and psychological (Andrews & Roberts, 2012). In this study, the hospital is the key space where parents experience this liminality.

Hospitals as Liminal Spaces: The patient experience in a hospital, and even the physical building itself can be perceived as a liminal space, as patients and their families attend for life changing or life-saving procedures. Patients remove themselves from everyday life and live in the highly charged environment where their previously known world changes (McKechnie, Jaye, & MacLeod, 2010). For many, the experience of being in hospital brings a new identity with their diagnosis defining who they will become in the future (Long, Hunter, & van der Geest, 2008). The transitions however do not always follow a predetermined pattern, so, for example, parents may have entered the hospital not knowing their child will die.

“Because transitions are not predetermined, they can become liminal spaces of communication, connection, encounter and renewal on different levels, for example, economic, sociocultural, and ecological.” (McKechnie et al., 2010, p. 13)

The physical structure of the hospital can provide a shelter for the patient and their family, becoming a “beneficial helper” as it takes over some of the responsibilities from family (Dahlborg Lyckhage & Lindahl, 2013, p. 604). In addition, the building can service to

provide temporal spaces for families, where even “the corridor and public spaces as contributors of communities that deliver care” by providing shelter away from the responsibilities of their former life, as it “sequesters and protects the liminal from the community” (McKechnie et al., 2010, p. 26).

2.2.3. Occupants of the “Liminal Space”

In this section, Van Gennep’s description of the characteristics of the occupants of the liminal space in Rites of Passage will be explored.

i. Neophytes: For Van Gennep (1903), an individual entering a liminal experience became a “neophyte” or novice. With its origins in the Greek language, “neophyte” refers to an individual who is new to an experience or activity. As Turner (1969) describes, the individual within the liminal stage has “few or none of the attributes of the past or coming state” (p. 94). They no longer occupy the world as they knew it, nor do they have the skills and abilities to manage the world to come. “During the middle phase of such a process the individuals involved are understood to be ‘no longer’ and simultaneously ‘not yet’.” (Wels, van der Waal, Spiegel, & Kamsteeg, 2011, p. 1). Turner (1967) describes neophytes in this liminal state as having lost their “classification” or place within the world, and yet not classified within the world they now occupy (p. 96). He describes the complexity of this phase thus:

“ ... one would expect to find that transitional beings are ... neither one thing or another; or may be both; or neither here nor there; or may even be nowhere ... and are at the very least “betwixt and between” all of the recognized fixed points in space-time of structural classification.” (Turner, 1967, p. 97)

Eaton & Hornborg (2009) describe this experience rather starkly as the neophyte leaving behind “a self that was culturally and socially embedded, with identities and relationships held within an over-arching worldview that provided orientation.” (p. 2). Such is the strength of this unique experience that McKechnie et al. (2010) believe that it dominates individual’s identity when they are within a hospital space.

ii. Communitas: However, Turner (1967) offers two concepts within this liminal space that can help and support the individual throughout their journey. His concept of “communitas” refers to the spirit of community that exists with others who are

also present within that space (Jordan et al., 2015). *Communitas* provides a sense of “social bonding and mutual support” within the liminal environment (Underwood & Rhodes, 2018). Braude et al. (2012) argue that, while the concept of *communitas* might more readily be perceived to belong to a pre-modern construct of health care, its core values of community and support are well suited to the tenants of today’s concepts of palliative care. The presence of siblings, family members or friends and staff provide parents with a sense of community and a sense of stability in a very unsettling time (Little, Jordens, Paul, Montgomery, & Philipson, 1998). If a strong sense of *communitas* can be experienced within this liminal space, this has a positive impact on the individual’s passage out of liminality (Underwood & Rhodes 2018).

iii. *Instructors:* The second concept that Turner (1967) referred to is the concept of “Instructors”. The space of the hospital incorporates what Turner (1967) refers to as “instructors” or “elders” who will provide the neophyte with a guide through the liminal process:

“... between neophytes and their instructors, there exists a set of relations that compose a “social structure” of highly specific type. It is a structure of a very simple kind: between instructors and neophytes there is often complete authority and complete submission ... it must be understood that the authority of the elders over neophytes is not based on legal sanctions; it is in a sense the personification of the self-evident authority of tradition.” (Turner, 1967, p. 99-100)

In a hospital, the medical and nursing staff are often seen as the instructors, determining the pathway forward and identifying and representing advances that provide for the greater good (Long et al., 2008). As a result, health care professionals can be highly influential for neophytes in this experience:

“[I]t is possible that the liminal time provides health care personnel with teachable moments that are an opportunity to mold [sic] the caring experience for both the caregiver and the care recipient by being sensitive to and knowledgeable about the rite of passage caregivers traverse.” (Gibbons, Ross, & Bevans, 2014, p. 433)

The concept of liminality introduced by Van Gennep (1903/1960) and developed by Turner (1967) provides an appropriate framework from which to examine the experiences of parents within an acute hospital facing the death of their child either within

the hospital or returning home to die after an extended hospital stay. It provides a structure for understanding the complex and challenging world in which parents find themselves, with limited contact with the world as they knew it and facing an unknown world ahead. As Hogue (2006) explains

“liminal times and spaces function to prepare participants for a new life to be lived under very different conditions or demands, in some cases actually reshaping their identities. But between ‘before’ and ‘after’ inevitably there appears a gap of uncertainty and disorder.” (Hogue 2006, quoted in McKechnie et al 2010, p. 12)

This concept of liminality provides a framework for understanding the experience of uncertainty and disorder typical of EOLC.

2.2.4. Liminality in Medicine

The concept of liminality has been used in many settings to understand the phenomenon of various human experiences at the margins between life and death (Braude, 2012; Froggott, 1997; Jordan et al., 2015; MacArtney, Broom, Kirby, Good, & Wootton, 2017; McKechnie et al., 2010). The use of the concept facilitates insight into the experience of terminal illness for individuals who live in a world where illness is an unwelcome visitor and modern life expectations are of wellbeing and good health for all. Little et al. (1998) argue that in the world of medicine which is now dominated by the technical complexities (such as experimental treatments, or the use of artificial life-sustaining technology), the concept of liminality allows us to contextualise and explain human experience of ill-health. It provides a more rounded account of that experience, rather than a concentration on simply the physical symptoms of an illness.

“The concept of liminality preserves the link between medical discourse and individual suffering by way of the body. This makes the concept powerfully translatable into clinical knowledge and practice.” (Little et al., 1998, p. 1492-3)

Various studies of the individual’s experience of illness, use the concept of being on a threshold or being in a liminal space. Little et al. (1998) describe the experience of patients with colon cancer from the perspective of liminality, describing the uncertainty and loss of control as they come to understand how their diagnosis impacts on their understanding of the world. Kelly (2008) speaks to the experience of the “living loss” of

those experiencing AIDS related dementia, describing how those close experience loss while the individual is still alive, as their faculties and personalities change. In examining the experience of terminally ill patients in Hong Kong, Ho, Leung, Tse, Pang, Chochinov, Neimeyer, & Chan (2013) use the concept of liminality to describe the “ambiguities” of this experience, characterised by “a cloud of confusion” about how they can manage everyday life within their medical care setting and a loss of “identity and personhood” (p. 954). Marshall, Grinyer, & Limmer (2019) describe the dual liminal experience for teenagers with cancer negotiating both the worlds of adolescence and of living with cancer. All of these examples highlight how the concept of liminality can promote the understanding of the individual’s experience of illness. Indeed, Little et al. (1998) point out that “its explication should therefore be important for those who provide health care, those who educate health care workers and those concerned to study and use outcomes as administrative and policy making instruments.” (p. 1485).

The concept of liminality has been found to fit well with the unknown and uncertain world of palliative care, with MacArtney et al. (2017) describing it as the concurrent experience as both living and dying. McKechnie et al. (2010) found that patients facing life threatening illness have so many demands for change and have to live with so much uncertainty, that they “suggest that individuals moved between a variety of liminal spaces and places but they never exit liminality” (McKechnie et al., 2010, p. 26). Other studies extend the concept of liminality in medicine to family caregivers, describing the transformative nature of that experience, identifying how carers too experience a change to their identity that is reflective of the ill person’s experience, in their seeking to understand and inform themselves about the illness in all its embodied features (Kelly, 2008, Gibbons et al., 2014).

i. Liminality in the Care of Children with Serious Illness or Who are Dying: This concept of liminality or “betwixt and between” has a useful place in the world of children’s palliative care. It allows those involved to recognise the transitions and ambiguities involved in this world (Carter, 2016) where medical certainties are few and uncertainty is a part of life (Gibbons et al., 2014). Particularly for children who experience complex, life altering conditions, the future is often unclear because of the lack of medical progress in finding a treatment or cure for their condition. In their research with families with children with life limiting conditions, Jordan et al. (2015) found that the concept of liminality provides a framework for understanding the “protracted and largely unknown

journey” that families face (p. 839). It recognises the family’s existence betwixt and between living and dying, often with an unknown trajectory or pathway.

“Throughout this time, just as their child exists ‘in-between’ life and death, so parents are suspended in a world that is neither one thing (their lives prior to their child’s illness), nor the other (their lives after their child’ illness has concluded).” (Jordan et al., 2015, p. 839).

For children and families experiencing life limiting conditions, living within this liminal space becomes a way of life to cope with the uncertainties (Rallison & Raffin-Bouchal, 2013). In keeping with Kelly’s (2008) findings that this liminal experience is extended to the “Intimate Circle of Care” that surrounds the unwell individual, it becomes clearer how parents and families are affected by this living in an uncertain world. Due to the intensity and complexity of this liminal experience concerning the death of a child, parents may be vulnerable to the possibility of “persistent liminality”, the idea that individuals don’t always return to their hoped for life after a liminal experience but are “more permanently unclassifiable in terms of the formal social roles they hoped to reclaim” (Crowley-Makota, 2005, p. 827).

Applying theories from social anthropology, this discussion has described how the concepts of Rites of Passage and liminality can be applied to the world of medicine, particularly the period of palliative care. While the aforementioned studies use these concepts to describe the experiences of adults who are dying and their carers, their applicability within the area of children’s palliative care is seen to be at its infancy.

2.3. Approaching the Study as a Narrative Inquirer

In order to provide an overview of this narrative approach to the research, the “theoretical considerations” in relation to the use of a narrative approach to research will be explored (Clandinin & Connolly, 2000).

The work of French Philosopher, Paul Ricour, strongly influenced the development of the “narrative” approach in philosophy (Dreyer & Pederson, 2009), emphasising the importance of the storytelling in shaping social phenomenon (Jovchelovitch & Bauer, 2000), allowing the researcher to gain an insight into the individual’s world (Hardwick & Worsley, 2011). Ricoeur believed that researchers create texts by engaging with

participants to describe their experience (Dreyer & Pederson, 2009), with the possibility of helping to reorganise the individual's world which has been rendered into disarray by the trauma or suffering (Dervish et al., 2017). Extending from its philosophical roots in Ricoeur's work (Czarniawska, 2004; Riessman & Speedy, 2007; Squire, 2013), narrative inquiry has become a well-established approach within the field of qualitative research (Chase, 2013; Hyvarinen, 2008). Now a popular approach across disciplines, its influences can be seen across the fields of literature, "history, anthropology and folklore, psychology, sociolinguistics and communication studies, cultural studies, and sociology" (Riessman & Speedy, 2007, p. 427). Within the social sciences, the "narrative turn" occurred in the 1980s (Elliott, 2005) encouraged by the humanist and anti-positivist approaches to human experience (Hyvarinen, 2008). The use of a narrative approach dovetails with the concerns within social science about social cultural and political discourses and therefore promotes its adaptation (Squire, 2008, p. 8).

With its roots in Aristotle's definition of a tragedy with a beginning, middle and end (Hyvarinen, 2008), narrative inquiry centres on the use of story to enquire into human experience, in both its public and private domains (Bamburg & Demuth, 2016; Clandinin & Connelly, 2000; Sools, 2013; Squire, 2013). It endorses the use of stories to gain a deeper understanding of the individual's world and how they understand their position within it "through the stories they tell" (Moen, 2006, p. 60) and highlights the richness of the individual's experience (Hickson, 2016). "The stories we tell about ourselves, the roles we play, the artefacts we construct, and the relationships we negotiate continually generate and revise who we are." (Swartz, 2009, p. 791). Narrative inquiry also invites the researcher to look for new possibilities within the experience being studied (Clandinin & Rosiek, 2007). It moves "beyond lived experience and worlds 'behind' the author" (Riessman & Speedy, 2007, p. 427) inviting the researcher to seek out these new possibilities within the research.

However, in order to have meaning, this study of human stories need to emphasise the chronology of the story, its meaning and social aspect (Elliott, 2005). Elliott's (2005) contention that it is the organising of a sequence of events into a story that means "the significance of each event can be understood through its relation to that whole" (p. 3). This examination of sequences of events allows the narrative inquirer seek out the "micro changes" that occur in peoples' lives which influence who they are as social beings. These micro-changes are

“the territory, the landscape within which development is forming, and within which then it becomes a territory for inquiry. So these are the kinds of developmental processes, ... where the issue of identity and identity formation, these types of changes that are taking place, are at the core of psychology; ... [and] a number of fields within sociology and anthropology. ... But there is this balance or navigation of what remains constant, and what changes.” (Bamburg & Demuth, 2016, p. 14-15)

Moen (2006) suggests that in order to approach a narrative inquiry, it is critical to understand its three basic claims which are:

1. “that human beings organize their experiences of the world into narratives”
2. “that the stories that are told depend on the individual’s past and present experiences, her or his values, the people the stories are being told to, the addressees, and when and where they are being told”
3. That “multivoicedness” takes place with narrative (p. 60)

In setting out these claims, Moen (2006) reflects the thinking of a number of other key writers in the field (Clandinin & Connelly, 2000; Hardwick & Worsley, 2011; Larsson & Sjoblom, 2010). However, she critically adds that, in addition to representing the voices of the participants with regard to personal stories, narrative inquiry also examines the participants collective stories “shaped by the addressees and the cultural, historical and institutional settings in which they occur” (Moen, 2006, p. 61). These collective stories are an inherent part of this narrative research project.

Narrative inquiry is described as developing an understanding of experience (Clandinin & Connolly, 2000) which promotes meaning making (Chase, 2013), a critical part of any experience of bereavement (Neimeyer, 2016). Of the many definitions that exist in relation to narrative research, this definition by Jirek (2017) provides a broad overarching understanding of the approach of a narrative inquiry:

“I define narrative research as an interactive process of storytelling, shaped by the immediate audience(s) and the broader social discourses, resulting in the

production of co-constructed accounts which have sequence and consequence.”
(p. 170)

This particular definition is chosen as it fits with the experience-centred, narrative approach adopted for this study, highlighting the interactive nature of the process of narrative inquiry, respecting the authority of the storyteller, while also acknowledging the influence of the inquirer on the process (Squire, 2013). It also acknowledges the potential for this type of inquiry to influence social discourses, particularly those of social injustice which is often at the heart of narrative inquiry (Clandinin, 2007).

However, concerns exist with regard to the nature and definition of narrative inquiry (Bold, 2012; Chase, 2013; Clandinin, 2007; Hyvarinen, 2008; Riessman & Quinney, 2005). Bamberg & Demute (2016) express a deep concern about the broad use of the term “narrative” and therefore the dilution of its meaning to become what they call a “narrative über Alles” [“Narrative above all”] position as an explanation for how lives are organised (p. 25). As a result of its use in such a wide variety of disciplines (Riessman & Speedy, 2007), the interests of researchers can be substantially different inviting different interpretations (Chase, 2013, p. 56). Riessman & Speedy (2007) raise concerns about the “tyranny” of narrative, in that it can be interpreted so broadly as to not have a true meaning. Hardwick & Worsley (2011) argue that broad definitions of narrative bring challenges for the narrative inquirer as to how to appropriately reflect the meaning intended by the storyteller, bringing a critical focus to the heart of what narrative inquiry is trying to achieve. They ask “[h]ow do we tell someone else’s story as they wished it to be told?” (Hardwick & Worsley 2011, pg 124-125).

Many narrative inquiry texts contain at least a section or even a chapter on these difficulties and express concern as to their impact on the field (Bold 2012; Clandinin, 2007; Riessman & Quinney, 2005; Squire, Andrews & Tamboukou, 2008). According to Chase (2013) “... it is easier to identify complexities and multiplicities in the field of narrative inquiry than it is to identify commonalities” (p. 74). Clandinin (2018) however suggests that narrative inquiry does not lend itself to always being straightforward, with its inherent tensions as to what stories to include or not include, or what particular analytic approach to adhere to – he suggests “There’s no smoothness—it’s always messy” (Clandinin, 2018, p. 20). In order to address some of these concerns, Bamberg & Demute (2016) encourage narrative inquirers to counteract this overuse of the term by ensuring clarity and transparency in their approach and in being explicit in the methodological

approach to their work. In order to do this, a clear approach to narrative inquiry adapted for this study is outlined below and in Chapter 4, in order to provide transparency and openness as to the methodological approach adopted.

In this study, I adopted an experience-centred narrative research approach (Squire et al., 2013; Squire, 2008). The experience-centred narrative approach

“rests on the *phenomenological* assumption that experience can, through stories, become part of consciousness. It also takes a *hermeneutic* approach to analysing stories, aiming at full interpretation and understanding ... it offers a highly appealing conceptual technology. It is indeed the dominant conceptual framework within which current social-science narrative research operates. It is perhaps most often and widely related, across disciplines, to the work of Paul Ricoeur (1984), which provides a useful reference point for this section.” (Squire, 2008, p. 16.)

Squire (2008) adds that this approach does not offer the analytic guidelines provided by a more structural approach but does provide a “conceptual technology” from which to view the research. According to Clandinin and Connolly (2000), such a structure invites an inquirer to take a multidimensional approach to viewing the research.

A narrative approach to research provides a framework for approaching the entire research process, not simply the process of analysis. For some, narrative represents a world view, a way to approach all aspects of both practice and research. Encompassing his social work beliefs and philosophy in the development of his narrative practices, Michael White, who, together with David Epston, founded the narrative approach to therapeutic interactions, suggested that narrative is “an epistemology, a philosophy, a personal commitment, a politics, a practice, a life” (White, 1994a, p. 82, quoted in Furlong, 2008, p. 404). It is critical, therefore that the researcher approach a study using narrative as a “frame of reference” (Moen, 2006, p. 57) encompassing the entire study process (Hickson, 2016). According to Connelly & Clandinin (1990), narrative inquiry is “both the phenomenon and the method. Narrative names the structured quality of experience to be studied, and it names the patterns of inquiry for its study” (p. 2). Indeed, Sools (2013) summarizes the approach as undertaking a detailed inquiry that focus on the sequence and actions within the texts. Elliott (2005) elaborates on this point by suggesting that within narrative inquiry, researchers need to attend to two types of story:

firstly the story provided by the research participant, and secondly, “the accounts we may construct as researchers to make sense of the social world, and of other people’s experience” in which researchers “present social and historical knowledge” (p. 13). Moen (2006) adds that because interpretation takes place throughout the “entire research process”, then it is essential that the inquirer ensures that all aspects of the enquiry are taken into account when developing understanding and knowledge. Reflecting the ongoing circular interpretive process within a narrative approach, Clandinin (2007) observes how researchers adapting a narrative approach use the terms “narrative inquiry” as well as the more traditional “narrative research” (p. xiii).

2.4. Ideas from Narrative Practice that can Influence Children’s End of Life Care

In order to integrate the findings of this study into discussions of the social context of the participants, and to develop a proposed framework for a narrative approach to children’s EOLC, an examination of some of the key concepts developed within the school of narrative practice will be undertaken. With their origins in a worldview that “enable an understanding of people and problems that is both respectful and hopeful” (Lainson 2020, p. 65), the inclusion of concepts of narrative practices is intended to offer an alternative perspective within the very difficult and challenging world of children EOLC. The exploration of these concepts will serve to support the discussion of the finding and the proposed narrative framework or map of hospital-based EOLC for children. It further supports the proposition that using a narrative framework may allow for the creation of alternative stories or meanings for the families and the staff involved in providing psychosocial care to a child and their family around the time of the child’s death in the hospital. As Hedtke (2014) proposes:

“Narrative approach allows psychosocial teams to stand alongside children who have ... life-threatening illnesses, and their families at critical times and to create stories of agency. Rather than dwelling on stories of loss and despair that potentially enfeeble families, a narrative approach builds on stories of strength that engender hope by asking questions that separate the person from the problem. Developing such stories supports people in taking action It also facilitates the formation of a legacy that can sustain family members, even after the death of a child. This legacy serves as the foundation for remembering the dead, folding their stories into the lives of the living, and constructing lines of

relational connection that can transcend physical death. Not only do families benefit from this approach, but the psychosocial team that provides professional and medical services can be uplifted through witnessing practices of strength and love in the face of hardship.” (p.4)

The inclusion of these concepts within the framework that supports this study is strongly based on the possibility of reducing practices that “enfeeble” families. It further reflects the more recent developments in the narrative theory that suggests an emphasis on sense-making process through which alternative stories can be explored (Chase 2013).

2.4.1. Overview of Key Concepts from Narrative Practice

In order to contextualise the discussion about the particular practices that will be highlighted from narrative practice³, a brief history of their development is provided. In relation to this study in particular, the connections between the framework of liminality and narrative practices will be emphasised as the threads are identified and the connections made:

“... a research text looks for the patterns, narrative threads, tensions and themes either within or across an individual’s experience and in social settings”.
(Clandinin & Connolly 2000, p. 132).

The concept of liminality has provided a social context for the experience of a child’s death and the complex and confusing experiences for those who are going through this rite of passage. Within this discussion, four concepts from narrative practice will be highlighted as providing opportunities for the creation of alternative stories in children’s EOLC. The creation of these alternative stories can help to reduce the confusion and complexity within those liminal experiences. The concepts chosen from narrative practice are: externalising conversations; reauthoring conversations; remembering conversations and definitional ceremony. Each of these practices is attributable to the work of Michael White and David Epston, who were central to the development of narrative practices (Lainson, 2020, p. 43). However, it is important in this study to

³ The term “practice” will be used throughout this discussion due to the concerns that White (1990) raises about the connoted meaning of the word “therapy” suggestive of a “cure” (p. 14)

examine their connections to those who influenced their work, particularly as they connect with the framework of understanding, developed for this narrative inquiry.

It should be noted that this outline does not allow for a full exploration of all of the influences on White and Epston's work, but highlights those that are pertinent to this study. However, it would not be possible to fully understand their work without mention of Michel Foucault's writings on power which is a fundamental pillar of White and Epston's (1990) approach. Foucault examined the nature of power and the impact that it had on individuals' lives. In particular, he examined how society could create a negative discourse about individuals who experienced struggles in life that as a consequence diminish their status in society (Foucault, 1980).

"These struggles are not exactly for or against the "individual" but rather they are struggles against the "government of individualization." ... What is questioned is the way in which knowledge circulates and functions, its relations to power. In short, the *regime du savoir [management of knowledge]*" (Foucault, 1980, p. 781).

Through his study of madness and illness for example, Foucault became concerned about how the power attached to knowledge, in particular how the concepts of "normal" and "abnormal" were applied to subjugate an individual's agency (Freeman & Combs, 1996). White (2007) explained that paying attention to how power operates within society is important when individuals are experiencing "inadequacy, incompetence, and personal failure" when they feel they have failed to "reproduce these norms categoriz[ing] people as "personal failures" in their own and each other's eyes" (White, 2007, p. 268). Narrative practice therefore pays attention to the meanings that people attribute to the power that hold stories of negativity in their lives.

Outlined below is a table that categorises the connections between major influences identified by White and Epston (1990) who in turn have influenced other narrative theorists and whose ideas are central to the interpretation of the findings in this study:

Influencers	Influenced/ Influencer	Influenced
<i>Arther Van Gennep</i> (b. 1873 – d. 1957)	MICHAEL WHITE (1948- 2008)	Lorraine Hedkte
<i>Lev Vygotsky</i> (b.1896 – d. 1934)		John Winslade
<i>Paul Ricoeur</i> (b 1913 – d. 2005)		David Newman
<i>Jerome Bruner</i> (b. 1915 – d. 2016)		David Densborough
<i>Victor Turner</i> (b. 1920 – d. 1983)		Jim Duvall
<i>Edward Bruner</i> (b. 1924 – d. 2020)		Laura Berés
<i>Clifford Geetz</i> (b. 1926 – d 2016)		Kristin Lainson
<i>Barbara Myerhoff</i> (b. 1935- d. 1985)	DAVID EPSTON (b. 1944 -)	

Figure 1: *Map of Influences Relating to this Narrative Inquiry (Developed from White & Epston 1990, Denborough 2014)*

In this map of influences on White and Epston’s work, the connectedness between the thinking and ideas from the worlds of anthropology and psychology can be seen. Having worked together for a number of years, White (a social worker) and Epston (an anthropologist) believed that it was important to acknowledge the influences on their work and so brought together their thinking and enumerated their influences in their 1990 seminal text “Narrative Means to Therapeutic Ends”. The discussion in the next section

will highlight the influence of each of these thinkers on White & Epston's different concepts highlighted within the discussion that follows.

2.4.2. Externalising Conversations

According to White (2007), externalising conversations provide an opportunity to explore alternative understanding about problems or concerns by "objectifying the problem" (p. 9). A central concept of narrative practice (Carr, 1998), these conversations prompt the development of a perspective that problems are separate from the people who experience them and can therefore be named and talked about (White, 2004). "When told in the context of an externalizing conversation, people's stories almost always become less blame and guilt ridden and less restrictive" (Combs & Freeman, 2012, p. 1044). Externalizing conversations allow people adopt a perspective that their problems are disconnected from their identity (Carr, 1998) and, as a result, diminish the marginalisation that people can experience through labelling or dominant beliefs.

"In fact, I believe that one of the primary achievements of externalising conversations is this unpacking of the thin conclusions that people have about their own and about each other's identity. In this activity, these conclusions are deprived of the truth status that has been assigned to them – these conclusions cease to carry the authority that they did." (White, 2004, p. 124)

Critical to an externalizing conversation is the establishment of an understanding of how the problem is affecting the person's life, by recognising the multi-layered possibilities in their narrative (Duvall & Béres, 2011, Lainson, 2020).

This process is highlighted by the now widely used phrase in narrative practice, "rescuing the said from the saying of it" (Denborough, 2011). This concept has its origins in the work of Paul Ricoeur (1971) (Newman, 2008). In his 1971 essay, Ricoeur characterises living speech as a "fleeting event" and raised concerns about how that speech can be fixed or inscribed (p. 531). He elaborated by describing how, in capturing everyday speech in writing, though an interview text for example, we can establish the intentionality of the speaker.

"What in effect does writing fix? Not the events of speaking but the "said" of speaking where we understand by the said of the speaking that intentional

exteriorization constitutive of the aim of the discourse thanks to which the *sagan* – want to become *Aus-sagan* – the enunciation, the enunciated. In short, what we write, what we inscribe is the *noema* of the speaking. It is the meaning of the speech event, not the event as an event.” Ricoeur (1971, p. 532).

Ricoeur later explained the intentionality in speech as the “*vouloir-dire*” (Moran, 2002, p. 5) which can be translated to mean “wanting to say”, his use of the subjunctive verb denoting an expression what is imagined or wished or possible (Hedtke & Winslade, 2005, p. 199). According to Newman (2008), Geetz later developed this idea by suggesting that the retention of what was said through inscription allows the meaning to persist in way that the speaking cannot. Newman (2008) adds that in narrative therapy, this practice of “rescuing the said from the saying of it”, allows the identification of

“those little gems – those words that are mentioned, sometimes as an aside – point us somewhere more generative and become more solid when pulled out of a conversation, held up, examined, ‘rescued’ and used in a document of some kind.” (Newman, 2008, p. 25)

Externalising conversations allow for this identification of “those little gems” representing the possibility of a different story, or a different outcome in problem saturated conversations.

2.4.3. Re-Authoring Conversations

Within narrative practice, similarly to narrative inquiry, stories are defined as “events linked in sequence across time according to a plot” (Morgan, 2000, p. 4). White (2007) describes how people he encounters in narrative practice often bring stories that have themes that “reflect loss, failure, incompetence, hopelessness, or futility” (p. 61), usually referred to as “problem-saturated” stories (Beaudoin, 2005). Examining the work of Edward Bruner (1986), who was an anthropologist studying the Native American Tribes of North America, White (1990) was stuck by Bruner’s reinterpretation of the dominant perspective of the tribes lives as “broken down” and “disorganised” to one of resistance, allowing for the possibility of a different outcome to the Native American struggle for their rights (p. 10-11). White (1990) goes on to report that

“the structuring of a narrative requires recourse to a selective process in which we prune ... those events that do not fit with the dominant evolving stories that we and others have about us. Thus, over time and of necessity, much of our stock of lived experience goes unstoried and is never “told” or expressed” (White, 1990, pg 11-12).

White elaborated further on this possibility of other stories by using the work of Jerome Bruner (1986). In his examination of literary texts, Bruner (1986) described how all good literary texts leave gaps within the story, allowing the reader to speculate or wonder about what that absent story is (White, 1990). White (2007) suggests therefore that these gaps or absent stories allow the development of other or re-authored stories.

The purpose of re-authoring stories is to engage individuals “in the re-authoring of the compelling plights of their lives in ways that arouse curiosity about human possibility and in ways that invoke the play of imagination” (White, 2007, p. 75-76). He also cautioned that at times, these were not just alternative, but “subordinate” stories, connected to the dominant powerful story, as described by Foucault (Winslade & Hedtke, 2008). Re-authoring stories can facilitate the separation of the identity of the individual from the “problem”, offering other possible stories to be created (Beaudoin, 2005). In order to listen for these stories, the narrative practitioner looks for “unique outcomes” (White & Epston, 1990). Unique outcomes are incidents that the person identified in their story where the problem did not dominate their lives, allowing them to “engage in preferred ways of being that are more congruent with their values.” (Beaudoin & Zimmerman, 2011, p. 6). The highlighting of these unique outcome is the basis for re-authoring a problem dominated story to allow the individual to see the possibility for a different choice.

2.4.4. Remembering Conversations

White (2007) talks about Remembering Conversations as “shaped by the concept that identity is founded upon an “association of life” ... [with] a membership composed of the significant figures and identities of a person’s past, present, and projected future, whose voices are influential with regard to the construction of the person’s identity” (White, 2007, p. 129). The concept of remembering conversations originated in the work of social worker and anthropologist Barbara Myerhoff (1992). Myerhoff worked with a small population of older Jewish people who had moved to the US in the early in the 20th

Century from Eastern Europe examining how, particularly on the death of one of their members, they marked and celebrated the death, often through the traditions of their now lost history that had been wiped out by the Holocaust (Myerhoff, 1984). In incorporating these concepts into his work with the bereaved, White (1988) developed the concept of remember conversations in order to “Say Hullo Again” (sic) facilitating the “reincorporation of the membership of the dead person in the ongoing community of the living” by maintaining and staying connected to the meaning of the dead person’s life (Hedtke & Winslade, 2005, p. 198). The critical importance of remembering following a death is highlighted by the work of narrative practitioners Lorraine Hedtke and John Winslade (2005, 2014, 2016, 2020). Their premise is that by being denied of opportunities to speak about the loved one who has died, individuals’ grief can be exacerbated. “When the parent of a dead child is judged for continuing to speak about their child ... opportunities to form meaning and sustain connections limit the possibility for new relationship to take place between the living and the dead” (Hedtke 2020, p. 457).

2.4.5. Definitional Ceremony

In addition to remembering, Myerhoff (1992) observed how the population she was working with created public ceremonies to remember the dead that highlighted public displays of their Jewish tradition, which Myerhoff saw as a ritualising process. Myerhoff was strongly influenced by the work of Victor Turner, particularly his work on the evolution of the earlier work of Van Gennep’s Rites of Passage, liminality and his own evolving thinking about ritual (Kaminsky, 1992). In Turner’s later writing, he elaborated on the use of ritual within Rites of Passage, and defined ritual as “distinctive phases in social process, whereby groups or individuals adjust to internal changes and adapt to their external environment” (Turner, 1967, p. 158). In her essay on this concept, “Life not Death in Venice” (1992), Myerhoff explained:

“One of the most persistent but elusive ways that people make sense of themselves is to show themselves to themselves, through multiple forms; by telling themselves stories, by dramatizing claims in rituals and other collective enactments; by rendering visible actual and desired truths about themselves and the significance of their existence in imaginative and performative productions” (Myerhoff, 1992, p. 257).

This ritualization of death allowed the community not only to honour the dead person but to define the loss in terms of their membership of the community and the meaning of the death to that community (Hedtke & Winslade, 2005; Swartz 2009). Myerhoff (1992) named these process as “definitional ceremonies” to highlight the meaning of the loss and to allow for those outside of the process to understand better the internal experience of the community who had experienced the death. Building on these ideas, White and Epston (1990) reported that they adopted these ideas into narrative practice in order to promote the “survival and consolidation of new meanings, but also to a revision of the pre-existing meanings” (p. 191). Definitional ceremonies remain a key part of narrative practice (Denborough, 2014; Moxley-Haegart, 2015; Swartz, 2009).

In addition to the concepts of Externalizing Conversations, Re-authoring Conversations, Remembering Conversations and Definitional Ceremonies, two other key concepts developed by Michael White will be used in the development of the “Map of Narrative Practice in Children’s End of Life Care” within this study. Firstly, White (2007) explained his use of the concept of “Maps” to structure and explore other possibilities within the therapeutic conversation. Influenced by the work of psychologist, Jerome Bruner (1986), White observed similarities in the experience described by Bruner of an individual reading a literary text, where they use previously held knowledges or Maps, which facilitate the reader’s understanding of the new territory, which is the literary text. White (2007) liken this process to the identification and development of new stories within narrative practice –

“when people first engage in therapeutic conversations in which they reconstruct the stories of their lives, it often seems that they are departing from the familiar and embarking on journey to new destinations without maps” (p. 76).

The creation of therapeutic maps within narrative practice allowed for the creation of new and alternative stories, allowing for the creation of different possibilities in individuals’ lives.

In addition, the concept of “scaffolding” will be used. Based on the work of Lev Vygotsky, a Russian psychologist, White (2007) described the concept of “*scaffolding*” therapeutic conversations with people with whom we work. The purpose of scaffolding in therapeutic conversations is to structure a conversation from problem to alternative story lines opening up possibilities and alternatives (Duvall & Béres, 2011). In order to do this in a safe and structured way, the stories that are “known and familiar” or dominant narratives

are explored, with the development of alternative or “possible to know” narratives through the exploration of exceptions to the dominant narrative (Hedtke & Winslade 2005, White 2011).

In applying these ideas to the world of the dying child in a hospital, this research will invite description of both the dominant and exceptional narratives experienced by parents, siblings and staff who are familiar with this world, developing the “threads” that have already appeared as exceptions within the interview texts. By gathering the stories of those who have been through this experience, an alternative conversation could be scaffolded to facilitate the emergence of those “exceptions”, allowing a different voice to unfold into a world that is currently dominated by the power of the medical narrative. In relation to working with dying children and their families, Hedtke (2014) concludes that this approach can be helpful in “disrupting stories of despair”, in moving from expert led conversations to collaborative conversations by valuing the family’s knowledge, and in creating opportunities, fostered through reauthoring conversations for the development of agency and hope (p. 4).

2.5. Conclusion

This chapter introduced key concepts of the theoretical framework that supports this study. Examining the applicability of taking a social constructionist approach to death and bereavement, I have shown how such an approach can allow the interdisciplinary staff working with families at children’s EOLC to acknowledge how their involvement and actions can support the family in very meaningful ways. Examining the concepts of Rites of Passage and Liminality have aligned with the social constructionist approach to death, opening up the possibility that the social context between parents and staff can influence how parents manage this liminal experience, both at the time they are within the hospital, but also when they return to their own communities, after their child had died. The in-depth explanation of the narrative framework chosen for this study demonstrated how, in examining the stories that people tell of their experiences, the possibility of identifying new and alternative narratives about that experience are created. A description of various approaches used within narrative practice that encourage and support the opening up of those alternative stories is included as they support the proposed “Map of Narrative practice at End of Life Care” which is developed within this research.

CHAPTER 3: INTRODUCTION TO CHILDREN'S PALLIATIVE CARE AND LITERATURE REVIEW

This chapter presents an introduction to the field of children's palliative care ("CPC") and EOLC to provide an overall context to parent and staff experience of the death of a child. A full literature review of the field of CPC is beyond the scope of this study. Instead, the literature review undertaken, as outlined below, centres, firstly, on the experience of parents during the EOLC of their child and, secondly, of the staff who work in this area. The chapter opens with an overview of the approach to the literature review. The chapter then proceeds to a detailed discussion of the findings from the literature review of both parent and staff experiences.

3.1. Approach to the Literature Review

The purpose of a literature review is to highlight findings from academic studies in the area under study, demonstrating how they have been discussed within the literature and to summarise the main concepts (Nakano & Muniz, 2018) in order to present a review of what is already known about this area.

3.1.1. Literature Review from the Perspective of Parents

I first examined the relevant literature that explores the experience of parents as their child is dying, in particular the psychosocial challenges for families entering this complex world. For this literature review, databases searched included: ASSIA (Applied Social Science Index and Abstracts); Social Science Index; PubMed; CINAHL (Cumulative Index to Nursing and Allied Health Literature) and PsychINFO. The literature search was carried out in December 2017-January 2018 and a final update carried out November 2020. The research question used to evolve the search terms was: *"What are the experiences of parents during children's hospital-based EOLC?"*.

From this question, the following terms and inclusion/exclusion criteria were developed for the search strategy:

Area of Search	Search Terms
Parents	[end of life OR terminally ill OR terminal care] [paediatric OR pediatric OR child*] [experience* OR perception* OR attitude* OR view* OR feeling*] [parent* OR mother* OR father*]
Inclusion Criteria	Published from 2000 onwards Peer reviewed Written in English
Exclusion Criteria	Articles that exclusively studied <ul style="list-style-type: none"> - the experience of parents within the broader experience of palliative care - home or hospice-based deaths - parents of adult children - adult ICU settings - bereavement

Table 3: Search Terms and Inclusion/Exclusion criteria for publications - Parents⁴

Hand searches were also carried out for related articles using reference or citation lists.

The literature was reviewed to provide an overview of the experience of parents. In order to provide cohesion and clarity to this literature review, the discussion was grouped into three sections:

- 1) Experience of the death of a child;
- 2) Long-term impact of the death; and
- 3) Emerging themes from the literature.

Each of these topics will be discussed in detail in Section 3.2 of this Chapter.

3.1.2. Literature Review from the Perspective of Staff

The second task I undertook was a review of the literature on the experience of staff providing children's EOLC. For this literature review, databases searched included: ASSIA (Applied Social Science Index and Abstracts); Social Science Index; PubMed; CINAHL (Cumulative Index to Nursing and Allied Health Literature) and PsychINFO. The literature search was carried out in December 2017-January 2018 and a final update

⁴ Full details of the literature search undertaken can be found at Appendix 2.

carried out November 2020. The research question used to evolve the search terms was: “What are the experiences of staff during children’s hospital-based EOLC?” From this question, the following terms and inclusion/exclusion criteria were developed for the search strategy:

Area of Search	Search Terms
Staff	[end of life OR terminally ill OR terminal care] [paediatric OR pediatric OR child*] [experience* OR perception* OR attitude* OR view* OR feeling*] [health care worker* OR health care professional*]
Inclusion Criteria	Published from 2000 onwards Peer reviewed Written in English
Exclusion Criteria	Publications with an exclusive focus on <ul style="list-style-type: none"> - neonates⁵ or based exclusively in neonatal intensive care units in maternity hospitals - home or hospice-based deaths - medical care

Table 4: Search Terms and Inclusion/Exclusion criteria for publications - Staff⁶

Hand searches were also carried out for related articles using reference or citation lists.

The literature reviewed provided a detailed description the experience and challenges for staff providing end of life care. The discussion of the findings from the review of the published articles was collated into four subsections:

- 1) Working with families at EOLC;
- 2) Communication and relationship building;
- 3) Impact of children’s EOLC on staff; and

⁵ Children in the first 28 days of life.

⁶ Full details of the literature search undertaken can be found at Appendix 2.

4) Role of the Social Work in children's EOLC.

Each of these topics will be discussed in detail in Section 3.3 of this Chapter.

3.2 The Experience of Parents at End of Life Care

Care of the child's family, particularly their parents, at EOLC is an essential part of the care provided (Widger & Wilkins, 2004; Zimmerman, Cignacco, Eskola, Engberg, Ramelet, Van der Weid & Bergstraesser, 2015). In order to explore in detail the experience of parents at EOLC, a literature review was undertaken. This section will provide a detailed discussion of parents' experiences and highlight their needs at EOLC, drawing from the review of the literature.

Research in this field examining parental experience often concentrated on the Paediatric Intensive Care Unit ("PICU") or the Neonatal Intensive Care Unit ("NICU") where most children die⁷ and was undertaken by medics, nurses and academic researchers. The field is dominated by research in the area of cancer care⁸ again undertaken by doctors, nurses and academic researchers. A small number of articles describing direct research with parents involved other professions such as psychology (Baughcum, Fortney, Winning, Shultz, Keim, Humphrey, . . . Gerhardt, 2017). A substantial body of articles based on systemic reviews or meta-analysis also exist that

⁷ (Butler, Hall & Copnell, 2018; Cacciatore, Thieleman, Lieber, Blood & Goldman, 2019; Currie et al., 2016b; Donnelly, Downing, Cloen, Fragen, Gupton, Misasi, & Michelson, 2018; Gilmer, Foster, Bell, Mulder & Carter, 2013; Liberman, Pham & Nager, 2014; Lotz, Daxer, Jox, Borasio & Fuhrer, 2017; Midson & Carter, 2010; Montoya-Juárez, García Caro, Schmidt-Rio Valle, Campos Calderón, Sorroche-Navarro, Sánchez García, & Cruz Quintana, 2013; Steel, 2005; Tan et al., 2012; Zimmerman et al., 2015; Zimmerman, Bergstraesser, Engberg, Ramelet, Marfurt, Russenberger, Von der Weid, . . . Cignacco, 2016)

⁸ (Heath, Clarke, McCarthy, Donath, Anderson & Wolfe, 2009; Hendricks-Ferguson, Pradhan, Shih, Gauvain, Kane, Liu & Haase, 2017; Hendricks-Ferguson & Haase, 2019; Hinds, Oakes, Hicks, Powell, Srivastava, Baker, . . . Furman, 2012; Hunt, Valdimarsdottir, Mucci, Kreicbergs & Steineck, 2006; Monterosso & Kristjanson, 2008; Monterosso, Kristjanson & Phillips, 2009; Pritchard, Srivastava, Okuma, Powell, Burghen, West, . . . Hinds, 2009; Pritchard, Burghen, Gattuso, West, Gajjar, Srivastava, . . . Kane 2010; Robert et al., 2012; Saiki-Craighill, 2002; Wolfe et al., 2000; Xafix, Watkins & Wilkinson, 2016; Zernikow, Szybalski, Hübner-Möhler, Wager, Paulussen, Lassay, . . . Schmidt, 2019)

include all causes of deaths⁹ as well as from the oncology perspective¹⁰. Less is known about the experience of families whose child dies unexpectedly or suddenly (Goldstein, Lederman, Lichtenthal, Morris, Human, Elliott, . . . Prigerson, 2018; O'Malley, Barata, Snow, & American Academy of Pediatrics Committee on Pediatric Emergency Medicine and Emergency Nurses Association Pediatric Committee, 2014). While recognising that cultural norms are critical for families (Kongnetiman, Lai & Berg, 2008; Wiener et al., 2013), this is an under-researched aspect of EOLC.

While some published reports documenting Irish families' evaluation of services exist (for example, Cliona's Foundation, 2018; Irish Hospice Foundation/Laura Lynn, 2013), there is currently no Irish peer reviewed, published research on the experiences of families at EOLC of their child. However, the work of Price and her colleagues in Northern Ireland provides a clear understanding of parents' experiences of caring for children with life-limiting conditions (for example, Price et al., 2011; Price & McNeilly, 2009) from a nursing perspective.

Within the literature review, no one approach or theory in relation to the psychosocial care of families in EOLC was found. In order to provide a clear overview of this area, therefore, the major findings were reviewed and grouped into dominant themes.

3.2.1 Experience of the Death of a Child

In examining the experience of parents at EOLC, it is critically important to recognise the impact of dying on a family. For a child, their family is the centre of their world and their key support through illness and dying. "Death and dying should be perceived as a family event that likely throws the family out of balance and requires adjustment of all family members to the new family reality." (Mehta, Cohen & Chan, 2009, p. 236). Before commencing a discussion of the experiences of parents at the EOLC of their child, it is timely to point out that most of the research that will be discussed in this section is based on the experience of parents who are will or have already faced the death of their child. For the purposes of this discussion, I will use the definition of bereavement as

⁹ (Butler, Hall, Willetts & Copnell, 2015; Craig & Goldman, 2003; Eden & Callister, 2010; Garstang, Griffiths & Sidebotham, 2014; Laws, 2004; Longden, 2011; Mills & Cortezzo, 2020; Milstein & Raingruber, 2007; Tomlinson, Bartels, Hendershot, Constantin, Wrathall & Sung, 2007; Zaal-Schuller, de Vos, Ewals, van Goudoever & Willems, 2016)

¹⁰ (Harris, 2004; Heinze & Nolan, 2012; Hinds, Oakes, Furman, Quargnenti, Olson, Foppiano, & Srivastava, 2001; McCulloch, Comac & Craig, 2008; Montgomery, Sawin & Hendricks-Ferguson, 2016; Petersen, 2020; Ranallo, 2017; Von Lutzau et al., 2012)

“encompassing the entire experience of anticipating a death, the death itself, and the subsequent adjustment to living” (Meert et al., 2009, p. 715 after Parkes and Weiss 1993).

In reviewing the experiences of parents before, during and after the death of their child, it is critical to remember that this is a devastating and life changing event (Garstang et al., 2014; Howes, 2015). Such a death shatters the assumptions that they have made about the world and their expectations for their child’s and their own lives, affecting the trust they have developed in the world, and their sense of mastery and control within their world (Darlington, Korones & Norton, 2018).

“The thought that one might lose one’s child through death is a terrifying one for parents. If the unthinkable actually happens and a child dies, parents are confronted with a world that has fallen apart. Their life’s hopes and expectations are thrown into complete disarray...” (Wijngaards-De Meij, Stroebe, Stroebe, Schut, van den Bout, van der Heijden & Dijkstra, 2008, p. 237).

It is critical to understand the complex nature of relationships within the family and their impact on the EOLC process, particularly the “unique and pivotal” role that parents occupy in their child’s life (Longden & Mayer, 2007). For a parent, the attachment process and the special care bond that exists with their child challenges and complicates the experience of facing such a death (Kearney & Byrne, 2011; Pianta, Marvin, Britner & Borowitz, 1996). Parents, within this attachment/caregiving context, are required to make decisions about their child’s well-being, their on-going treatment and (together with the medical team) the point at which it is appropriate to stop active treatment, requiring a reworking and resolution of that attachment/caregiving framework (Kearney & Byrne, 2015). These authors conclude that, in recognising the unique bond between parents and children, staff may come to recognise that unstable or unpredictable behaviours exhibited in an environment such as EOLC may be seen to be appropriate in the context of that bond.

The illness and death of a child also impacts on all family dynamics. In order to adjust to the assault on their world view that is brought about by their child’s dying, parents need to engage with their own emotional processes and may find it challenging to support other well siblings (Brooten & Youngblut, 2017; Dickens, 2014,) or their partner (Albuquerque, Pereira & Narciso, 2016; Hooghe, Rosenblatt & Rober, 2018).

For many parents, the death of their child occurs after months or years of managing the complex and challenging world that is the health care system, in which they become familiar with health systems and professionals (Darlington et al., 2018). Having learned to live with the impact of their child's illness, they then have to learn to manage an even more complex and stressful world where their child is dying (Cadell et al., 2012). The development of such complex coping strategies can be challenging.

“Parental resolution of a child's life-threatening diagnosis is a complex achievement. It reflects psychological models of the child, the child's medical condition, and the parent as a caregiver within the context of the attachment relationship” (Kearney & Byrne, 2011, p. 369).

Parents are at the heart of the care of their child with a life-threatening condition and carry with them at all times the significant burden of their child's anticipated death (Cadell, 2012). When a child's EOLC occurs after a sudden traumatic event, the family has little or no time to prepare, and staff need to develop a close relationship in a short space of time, ensuring that families are facilitated to say goodbye, providing as much information as possible as to the cause of death (Garstang et al., 2014; O' Malley, 2014).

When a family is told that their child is actively dying, the family face a crisis (Mehta et al, 2009). Whatever role is played by the parents, be that as the child's carer at home or if they are at the bedside in a hospital or hospice, the parents and family need to adjust to the existence of life-threatening illness within their family (Jordan et al 2016), which impacts on various dynamics within the family including their emotion, physical and financial lives (Monterosso et al 2007).

This need for adjustment, however, can often come in the face of a need to maintain normal family routines (Brody & Simmons, 2007, p. 152). The ability of any family to find a way of coping is based on the following factors: internal family strengths of rapid mobilization and reorganization; support from the health care team; support from extended family; support from the workplace; and changes in family appraisal (or their ability to view the experience as manageable) (McCubbin, Balling, Possin, Frierdich & Bryne, 2002, p. 105-108). If all of these factors are in place, then the family finds the strength to make the adjustments in roles and the emotional competency to manage the crisis of their child's final illness. “A life-threatening event alters family life, ... but new patterns of functioning can be instituted by families with the support of other informal and

formal resources” (McCubbin et al., 2002, p. 110). It is often, however, when one or more of these factors is not present that difficulties arise at end of life care.

In her Canadian study involving 8 bereaved families, Steele (2005) explored the changes that families need to make during their child’s illness, while at the same time trying to hold on to normal family life. She points out that many parents have already been through many losses with their child as their health deteriorates, slowly grieving each of the losses that are associated with their child’s deteriorating health. This anticipatory grieving is a feature of parents’ coping with the expected death of a child (D’Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Price & Jones, 2015). Parents need to be supported in their anticipatory grieving so as to help them to address their own emotional needs in order, in turn, to be able to deal with the other family issues they need to address, particularly the needs of their other children (Doorenbos, Lindhorst, Starks, Aisenberg, Curtis & Hays, 2012; Robert et al., 2012).

In addition, the toll of EOLC needs to be taken into account. In a qualitative hermeneutic phenomenological study carried out with 6 parents whose children died from cancer by a group of Swedish nurses, Bjork, Sundler, Hallstrom & Hammarlund (2016) further discuss the detrimental physical impact on parents’ energy levels, of dealing with the news that their child will die. They describe this experience for parents like “being covered by a wet and dark blanket” which aptly described the weight of exhaustion that parent can experience during this time of their child’s care. Steele and Davies (2006) add to this discussion by raising concerns that this exhaustion can impact on parents’ cognitive functioning, thereby affecting their ability to understand and absorb information and make decisions.

3.2.2. Identified Needs of Parents During End of Life Care

In order to create the following summary of the needs of parents during their child’s EOLC, a number of literature reviews¹¹ and original research articles¹² were examined.

¹¹ (Aschenbrenner, Winters, & Belknap, 2012; Griffiths et al., 2018; Heinze & Nolan, 2012; Longden, 2011; Marsac, Kindler, Weiss, & Ragsdale, 2018; Melin-Johansson, Sebire & Brierley, 2014; October, Dryden-Palmer, Copnell, & Meert, 2018; Petersen, 2020; Stevenson, Achille, & Lugasi, 2013; Stiffler, Birch, Campbell, & Cullen, 2017; Uveges, Hamilton, DePriest, Boss, Hinds, & Nolan, 2019; Virdun, Brown, Phillips, Lockett, Agar, Green, & Davidson, 2015; Weaver, Heinze, Kelly, Wiener, Casey, Bell, . . . Hinds, 2019; Xafis et al., 2016; Zaal-Schuller et al., 2016)

¹² (Arutyunyan, Odetola, Swieringa, & Niedner, 2018; Butler et al., 2018, Cacciature et al., 2019; Saiki-Craighill, 2002; Davies, 2005; Dussel et al., 2009; Garstang et al., 2014; Gilmer et al., 2013; Hendricks-Ferguson & Haase, 2019; Hinds et al., 2012; Longden, 2011; Lotz et al., 2017;

A small number of opinion articles were also included as they raised important points about parents' experience (Carnavale, 2007; Harris, 2004; Suttle, Jenkins & Tamburro, 2017; Gillion, 2018).

This literature highlighted areas that parents found important to them in children's EOLC; 1) need for excellent and clear communication and information provision; 2) involvement in decision making; 3) emotional and psychosocial support; 4) parental need to maintain parent/child relationships in life and death; 5) quality of care continues after the death of the child; 6) influence of service planning on parent/child quality of life; 7) alleviation of suffering; and 8) location of care. Each of these areas will be explored in the discussion that follows.

i. Need for Excellent and Clear Communication and Information: Good communication that is clear, honest and timely is an essential factor throughout a child's illness but particularly at end of life care¹³. Coad, Patel & Murray (2014) suggest that good communication underpins the relationship between parents and health care providers as it "forms the gateway to receiving and understanding information" in relation to the child's medical condition and status and affords parents "the opportunity to make choices about the time remaining to them" (p. 302). Good communication also creates a trusting environment in which the parents can have meaningful interactions (Suttle et al., 2017) and where staff can provide guidance for future care (Petersen, 2020). The need for good communication stems from the parents' requirement to be involved in decision-making about treatment, one of the most challenging aspects of parental responsibilities in EOLC (Tomlinson, Bartels, Hendershot, Maloney, Ethier & Sung, 2011, p. 2183).

The impact of good and compassionate communication between health care professionals ("HCPs") and families is highlighted by Cacciatore et al. (2019) in their qualitative research with 18 family members whose children have died in the United States. Most of the family members involved in the research were parents who emphasised how those interactions with HCPs influenced their EOLC experience, both positively and negatively, affecting their ability to manage the death going forward.

Martel & Ives-Baine, 2014; Michelson, Koogler, Skipton, Sullivan, & Frader, 2006; Midson & Carter, 2010; Price et al., 2013; Siden, Miller, Straatman, Omesi, Tucker, & Collins, 2008; Steele, 2005; Von Lutzau et al., 2012; Zimmerman et al., 2015; Zimmerman et al., 2016; Zernikow et al., 2019)

¹³ (Butler et al., 2015; Cacciatore et al., 2019; Heinze & Nolan, 2012; Hendricks-Ferguson & Haase, 2019; Hinds et al., 2012; Meert et al., 2009; Midson & Carter, 2010; Monterosso et al., 2009; Petersen, 2020; Short & Thienprayoon, 2018; Xafis et al., 2016)

Parents' clear recollection of the process of communication is reflected in Hendricks-Ferguson (2007) study. In her study, she found that the experiences of 28 parents in the US who were interviewed by telephone about their experiences of communications around EOLC options was both positive and negative. Parents recalled very clearly conversations with medical personnel that ranged from being helpful and supportive to very challenging. In addition, Hendricks-Ferguson (2007) reported that parents who experienced these conversations as delivered with compassion and understanding reported that they found it easier to transition to EOLC. Those who reported these conversations as negative, reported experiencing shock and surprise when EOLC was introduced. Another example of difficult conversations is in the technical area of a child's care, where staff need to find a language that helps families to understand the complex medical information that needs to be explained so that parents can full understanding the critical nature of their child's illness (Jones, Parker-Raley, Higgerson, Christie, Legett & Greathouse, 2008, p. 63). Other studies found that parents describe differing types of communication depending on the child's diagnosis (Monterosso et al., 2007) or the stage of illness (Butler et al., 2018).

In addition, barriers to good communication are characteristic of this area of care (Currie et al., 2016b; Marsac et al., 2018; Xafis et al., 2016). In their US based study with 10 bereaved parents whose child died in a NICU, parents reported that these barriers were not just due to difficulties in communicating with health care professionals, but also arose from practical problems such as travelling to the hospital or the financial difficulties of having to reduce their working hours to be at the hospital or because only one parent could take time off work to be at the hospital to communicate with the team (Currie et al., 2016b). In other studies, different factors existed such as the parents wanting to protect the child or themselves from having to face the possibility of death (Marsac et al., 2018) or staff's inability to meet those needs (Constantinou, Garcia, Cook & Randhawa, 2019). Indeed, it is not just the information provided by the teams that is important but the care with which it is imparted, so that parents are given the time that is needed to absorb these communications as their decision making abilities are compromised by the high emotions experienced during this time (Xafis et al., 2016).

The need for good communication does not cease with the child's death, with essential information to be imparted through post-mortem and other post death meetings, in order for parents to have full information about the details of their child's death (Garstang et al., 2014; Griffiths, et al., 2018).

ii. Involvement in Decision Making: Within the literature, parents reported the critical nature of being involved in decisions about their children (Butler et al., 2018; Copnell, 2005; Gilmer et al., 2013; Price et al., 2013). Influenced by their physical contact and impression of their child's health, parents go back and forth in their thinking about whether or not the correct decision was made about their child's care.

“Regardless if the parents had positive or negative experiences during the hospitalization and surrounding their infant's death or if the parents felt as if the best decisions were made for their infant, parents often reflected back on their decisions, questioning if the outcomes could have been different. From one sentence to the next, parents would state that they were at peace with decisions, but then wondered “what if?”.”(Currie et al., 2016b, p 483).

Parents value being aware of all of the different aspects of the child medical condition (Baughcum et al., 2017) so that they can be actively involved in decision making (Zaal-Schuller et al., 2016). Factors complicating decision making can be lack of appropriate information, use of complex medical language, as well as the large volume of complex medical information that may be available (Xafis et al., 2016). Despite these challenges, however, Forde & Linja (2015) highlights parents' perspective of the critical nature of their involvement in hospital discussions on the ethics of treatment decisions, with parents concluding that they would rather be present in order to hear all of the information put forward in making a decision about future treatment. Parent's spiritual beliefs, too, can also influence their thinking and decision making, particularly in relation to the cessation of active treatment (Arutyunyan et al., 2018)

However, the area of decision making about their child's future care is fraught with ethical and moral challenges (Carnavale, 2007). Decisions are rarely straightforward or simple (de Vos, Seeber, Gevers, Bos, Gevers & Willems, 2015). Parents can feel torn between wanting to be loyal to their child and given them every chance of recovery and being involved in a decision that will mean active treatment will stop and their child will die (Kars, Grypdonck, de Bock & van Delden, 2015). For some, advance care planning can diminish the intensity of the process with plans made in advance with trusted health care staff ensuring the child's best quality of life and avoiding suffering (Hammes, Klevan, Kempf & Williams, 2005). At the other extreme, public rancour between hospitals and parents leads to additional stress and heartache for parents (Gillion, 2018; Hammond-Browning, 2017).

iii. Emotional and Psychosocial Support: The need for emotional and psychosocial support from family, friends and professionals appears across the literature (Meert et al., 2009). Parents reported that they saw professional support as “the need for a caring, sustaining expert presence that reaches out in times of crisis” (Meert et al., 2009, pg 724) where even the simple tasks of finding your way around the hospital can be facilitated by a caring staff attitude. However, parents reported that they found a change in staff when the care approach moved from a cure focus to an end of life focus in the child’s care as staff adjust to this change. “Parents may sense this discomfort and interpret it as avoidance.” (Aschenbrenner et al., 2012, p. 521). A downside of the professional support provided was the bewilderment that parents experienced with the large number of staff from various disciplines that they encountered, especially in a highly technical environment like the PICU (Meert et al., 2009).

The emotional journey for parents at their child’s end of life is complex (Muskat, Brownstone & Greenblatt, 2017) and it is critical for parents to have the opportunity to express these emotions during EOLC (Meyer, Ritholz, Burnes & Truog, 2006). A compassionate presence by staff caring for the child provides a sense of acknowledgement for parents and a sense of being understood (Cacciatore et al., 2019). In addition, parents can experience complex emotions around the time their child dies which can be challenging even to acknowledge. For example, for some parents, a sense of relief can follow a child’s death as their suffering is ended and their struggle is over (Currie et al., 2016b).

In a longitudinal qualitative, descriptive study carried out in the US by Tan et al. (2012), 14 parents of 7 children born or diagnosed with life-threatening illness were interviewed regularly while their child was alive and receiving EOLC and further after they had died at six weeks and six months post death. In examining the experiences of this group of parents that had significance for them after their child’s death, Tan et al. (2012) found that preparation for death, continuity of care, and the opportunity for memory making were important to parents in their bereavement process. The importance of this type of support can provide parents with opportunities that can positively impact on their grieving process (Pritchard et al., 2009). In addition, it is not necessarily the type of support provided that has an impact, but rather the way that this support is received that counts (Melin-Johansson et al., 2014). Indeed, studies suggest that, in order for parents to experience staff support as helpful, parents’ expectation is that staff will make a concerted effort to recognise their child as a unique individual, and to acknowledge the family’s challenges at this time (Meert et al., 2009, Melin-Johansson et al., 2014).

iv. Parental Need to Maintain Parent/Child Relationships in Life and Death: In the EOLC of a child, it is critical to understand that, for a parent, their relationship with their child is a “major part of their personal identity” (Meert et al., 2009, p. 720) and spending time with their dying child is critical both at the time of death and in their bereavement process (Wijngaards-de Meij et al., 2008). Another helpful process for parents can be the opportunity for “memory-making” through the collection of small mementos or photographs around this time or immediately after the child’s death (Currie et al., 2016b; Martel & Ives-Baine, 2014; Stiffler et al., 2017; Viridun, Brown, Phillips, Luckett, Agar, Green & Davidson, 2015). Referred to as “memory anchors”, these items provide a physical connection for parents from the pre-death to the post death timeframe and provide comfort to them in their bereavement (Goldstein et al., 2018; Meert et al., 2009).

A highly technical care environment can compromise the parent’s ability to be physically present with their child to undertake “normal” parenting activities (Currie et al., 2016b). This “obligation of proximity”, where parents want and need to remain at the child’s bedside in order to feel they are doing their best to care for their dying children is common (Darlington et al., 2018). In addition, parents hoped that staff would continue to support them to encourage and nurture this parent child relationship, confirming their “non-abandonment” as parents during EOLC (Aschenbrenner et al., 2012), a need that continues in the immediacy after the child’s death (Davies, 2005).

v. Quality of Care Continues After the Death of the Child: In numerous articles parents recognized the on-going need for contact with the professionals who cared for their child during their last days which they described as helpful in their bereavement (Meert et al., 2009; Snaman, Kaye, Levine, Cochran, Wilcox, Sparrow, . . . Baker, 2017). The provision of on-going contact with staff such as attending funerals, sending cards, phone calls, and memorial services are valued by parents as they grieve the death of their child (Aschenbrenner et al., 2012; Snaman et al., 2017; Viridun et al., 2015; Zimmermann, Bergstraesser, Engberg, Ramelet, Marfurt-Russenberger, Von der Weid, N., . . . Cignacco, 2016). Indeed, Snaman et al. (2017) suggest that the provision of a full bereavement service including therapeutic support and referral to local services for parents who live at a distance from the hospital can become an empowering experience for bereaved parents who may become involved in the development and support of such a programme later on in their bereavement journey (Donovan, Wakefield, Russel & Kohn, 2015; Garstang et al., 2014).

v.i. Impact of Service Planning on Parent/Child Quality of Life at End of Life Care: In a number of studies, parents noted how the local policies and practices within a hospital influenced the care of their child (Melin-Johansson et al., 2014; Monterosso et al., 2007; Zimmermann et al., 2016). These practices include staff shift changes, rotation of medical personnel, or visiting policies. In particular, parents noted that it is critical to have professional staff with “specific paediatric knowledge and experience” care for their children (Monterosso et al., 2007). The continuity of care by the same professionals was also a key supporting factor as well as excellent written plans for the child so that parents’ wishes were clearly documented (Melin-Johansson et al., 2014). According to Zimmermann et al. (2016), ensuring that organizational systems work to provide “continuity and co-ordination of care” which parents believe is critical “in promoting caring, reducing parental frustration and enhancing parents’ confidence in the quality of their child’s care” (p. 11).

vii. Alleviation of Suffering: Addressing suffering in children’s’ EOLC is an essential element of care (Suttle et al., 2017). From a parents’ perspective, the management of their child’s difficult and painful symptoms is a critical part of the EOLC, resulting in the child being “as comfortable as possible and free from physical pain” (Melin-Johansson et al., 2014, p. 666). Parents whose children died from cancer have reported that their suffering has not been adequately addressed (Harris, 2004). In addition, parents’ definition of suffering extended to emotional suffering and the suffering caused by the child being separated from natural support systems (Montoya-Juárez et al., 2013). However, this can be a difficult area to judge as parents will sometimes report as distressing, symptoms that are part of the dying process for a child (Zimmermann et al., 2016).

viii. Location of Care: Location of the child’s death was found to be of lesser importance by parents than other practices at EOLC (Dussel et al., 2009). Early recognition, discussion and planning for a critically ill child can facilitate choice of location of death (Zernikow et al., 2019) and can lead to more home deaths (Dussel et al., 2009). While the location of a child’s death cannot always be planned, it needs to be kept in mind that for parents whose child dies in a PICU, the location can increase parent’s vulnerability to more long-term complications (Doorenbos et al., 2012). While children’s deaths occur in hospital, home and children’s hospices (Siden et al., 2008), most parents would express a wish for their child to die at home (Virdun et al., 2015) while others

would not express a preference or changed their minds (Noyes, Edwards, Hastings, Hain, Totsika, Bennett, . . . Lewis, 2013). It can therefore be critical to ensure that parents are provided with the opportunity to change their mind about location of death, so that families can have a location that best suits their needs at the time (Siden, et al., 2008).

ix. Culture/ Religious Beliefs/ Spirituality: Caring for a dying child can challenge parents' spiritual belief systems and this needs to be addressed within children's EOLC (Petersen, 2020). Steele and Davis (2006) report that, for the parents in their study, spiritual pain was part of their journey in caring for their sick and dying child. As parents struggle to understand why their child was ill, "they asserted that their struggle was an essential component of finding meaning and achieving acceptance of their plight" (Steele & Davis, 2006, p. 582).

Recognising and respecting a family's "beliefs, values, customs and traditions" is critical during the time a child is dying (Meert et al., 2009, p. 722). Parents advised that it is important that this be done on an individual family basis and that no assumptions about family beliefs or practices be made. Parents also report that their religious or spiritual beliefs impacted on the pathway of care for their child in that it provided guidance to them on decision-making, provided comfort and support, and provided a source of meaning for them in making decisions about their child's care (Arutyunyan et al., 2018; Uveges et al., 2019,).

The needs of parents during EOLC of their child have been outlined in detail in this literature review highlighting the crucial connection between these needs being addressed and the parents' management of their grief after the child's death (Tan et al., 2012).

3.2.3. Long-Term Impact

The traumatic experience that parents undergo when their child dies can leave them vulnerable to long-term consequences for their physical and mental health (Hunt et al., 2006; October et al., 2018). In a departure from the usual approach found in this body of research, several population studies carried out in Denmark provide information on the long-term effects of the death of a child on parents. Using robust qualitative analysis, the findings of Li, Precht, Mortensen & Olsen (2003) on the increased risk of mortality particularly to mothers, and Li et al. (2005) on the increased hospitalisation for mental health issues (again especially among mothers) highlight the very real long-term effects

of this type of death. The death of a child can result in marked psychological and physical complications for bereaved parents (Lannen et al., 2008) and “increased rates of first-time psychiatric hospitalization, and excess mortality from both natural and unnatural causes” (Meert et al., 2009, p. 713-714). While replication of these findings in other countries would be difficult due to the lack of a national system for the collection of such detailed information, such large population studies are important to highlight the very real long-term effects of bereavement of this kind. Following on from these studies and again based in Denmark, Wijngaards-de Meij et al. (2008) undertook a further qualitative study which identified the variables that impact on parental grieving, with lack of preparation for the death highlighted as having a negative effect. In addition, the social and economic impact needs to be recognised (Meert et al., 2009; Monterosso et al., 2007; Stebbins et al., 2007; van den Berg, Lundborg & Vikstrom, 2017) including the impact on the parents’ ability to work (Macdonald, Kennedy, Moll, Pineda, Mitchell, Stephenson, & Cadell, 2015) so that the complexity of long-term needs of parents is not underestimated. Monterosso et al. (2007) also identified the impact on parents of the community response to their death, as the community in their own struggle to deal with the loss, expecting that the parents will “move on” at a certain point in their bereavement. Dennis Klass (writing the introduction to Stebbins et al. 2007) summarises it well by describing how parents’ “whole world” is impacted by the death.

“Bereaved parents know that they don’t have just a psychological problem. ... When a parent dies, we lose a part of our past. When a child dies, we lose a part of our future, and that takes some getting used to. It is not a psychological syndrome. It is a life to be reorganised in light of the new and terrible reality.... The parents also know that much of their stress comes from the disconnect between their grief-filled world and the outer world. Friends don’t know what to say, so they act as if the death did not happen, or they say unhelpful things.” (Klass, writing in Stebbins et al., 2007, p. 1)

3.2.4. Emerging Themes within the Literature

Within this literature review, a number of emerging findings were highlighted that are pertinent to the present study including the involvement of parents in research, the meaning that parents attributed to hope within EOLC, and the emerging concept of post-traumatic growth for parents after the death of their child.

i. Involvement of Parents in Research: A developing body of literature highlights feedback from bereaved parents that involvement in research following the EOLC of their child can in fact be a positive experience for them (Butler et al., 2018; Currie, Roche, Christian, Bakitas, & Meneses, 2016a; Michelson et al., 2006; Tager, Battles, Bedoya, Gerhardt, Young-Saleme & Wiener, 2019; Tan et al., 2012). This particular thread in the literature commenced with Dyregrov's (2004) study in which all of participants reported that, while somewhat painful, they found the experience positive and none of them regretted participating. Additionally, participants reported a positive, therapeutic effect of telling the story of their bereavement and felt empowered by contributing to the knowledge in the field and the thought that their "story" might help others. These findings were similar to those in Currie et al. (2016a) in which parents reported the positive and cathartic effects of research participation. Clearly, being able to have a voice provides parents with a positive experience in their bereavement, allowing them an opportunity for altruism, a coping strategy that Tan et al. (2012) found to be an essential theme in coming to terms with their loss. Indeed, their voice can also serve to ensure that the identified improvements required in this field are put in place for families who will come after them. Such findings continue to be replicated, with an argument developing that the benefits of participation outweigh any concerns about negative impact (Deming, Wolfe & DeCoursey, 2020; Hynson, Aroni, Bauld, & Sawyer, 2006; Weaver et al., 2019).

ii. Meaning Parents Attribute to Hope: Another emerging theme from the literature is the meaning that bereaved parents attribute to hope during EOLC. The meaning and role of hope among parents of children with life-threatening illness remain relatively unstudied and is frequently viewed as hope for a cure. In a more evolved explanation of hope among parents whose children are dying, Barrera, Granek, Shaheed, Nicholas, Beaune, D'Agostino, Bouffet, & Antle (2013) suggest that parental hope during a child's illness and death is complex and multifaceted in nature. Many families report that the maintenance of hope can be a helpful factor in their management of their child's illness (Reder & Serwint, 2009; Liben et al., 2008; Wood et al., 2010). Indeed, O'Brien, Duffy & O'Shea (2010) report that hope can be a fundamental support in parents' coping in these circumstances. Tomlinson et al. (2011) in their research into decision making among parents who had children with a palliative cancer diagnosis found that hope was a key element in parents' decision to agree to palliative chemotherapy for their child, in the hope of a tiny possibility of cure, increased survival time and better quality of life for their child. In this study, parents rated hope as the most

important factor in decision-making, identifying their role as “bearers of hope when their child was dying” (Tomlinson et al., 2011, p. 2185). Additionally, Hill, Miller, Walter, Carroll, Morrison, Munson, . . . Feudtner (2014) found that hope was an essential element in parents’ ability to adjust their expectations during EOLC, a process the authors refer to as “regoeing”. Through this process of regoeing parents who were able to be hopeful could accept the need to abandon some of the goals they had set and substitute other more realistic goals for their child’s EOLC. It is therefore critical to accept the important function of hope, and the ability of parents to recognise the possibility that their child will die and at the same time hope for a miracle cure (Liben et al., 2008).

iii. Possibility of Post Traumatic Growth: There are threads appearing within the literature about the possibility of post traumatic growth for parents after the death of their child. When parents can find a personal and social meaning to their child’s life and death, then more positive resolution of their grieving can take place (Riches & Dawson, 1996). Steele and Davies (2006) report that, while the dominant message about caring for a child while they are dying was one of negativity, parents in their study identified aspects that were satisfying within that experience, reporting that they did not experience it as a burden. In more recent studies, the concept of “post-traumatic growth” has been described, involving “the regaining of equilibrium, the reformulation of dissolved assumptions about the world, and the renewed sense that life is worthwhile and purposeful” (Barrera, O’Connor, D’Agostino, Spencer, Nicholas, Jovcevska, . . . Schneiderman et al., 2009, p. 499). Barrera et al. (2009) declare a cautious note about these findings, reporting that there is no consistence with the findings of post-traumatic growth, with many variables within individual parent experience. These findings, however, highlight the possibility that, following the passage of time and with the appropriate support, personal growth is possible even after such a difficult bereavement (Albuquerque, Narciso & Pereira, 2018, Saiki-Craighill, 2002, Waugh, Kiemle & Slade, 2018).

The literature cited above provides a comprehensive overview of the themes occurring for parents in their experiences with children’s palliative care. However, a cautious note about the need to individualise each parent’s experience of this difficult time is critical, so that the review of the evolving themes in this area can only be seen as indicative of parental needs. This body of literature provides a very useful background for those seeking to understand and support parents through this experience. As Kearney & Byrne (2011) report

'[i]f we can support parents in their caregiving executive functions while understanding the psychological and emotional underpinnings of the caregiving systems and parental engagement itself, we can move inquiry forward in understanding parental needs for intervention during this most profoundly challenging time" (pg 367).

3.3. Interdisciplinary Team

This section examines key concepts within the literature on the provision of EOLC to children and their families by the interdisciplinary team within a paediatric hospital. The usual goal of children's health care is to cure (Forster & Hafiz, 2015). Within a medical setting, a child's death contravenes normal expectations, bringing about the possibility of both "professional embarrassment" (Kane and Primomo, 2001, p. 162) and "social embarrassment" (Howes, 2015, p. 42) due to the perceived multiple failures by staff because they did not save the child's life, they were unable to protect a child from harm and they were unable to fulfill the parents' wishes that the child would survive (Midson & Carter 2010; Morgan, 2009).

Working with children and their families at EOLC is both a privilege and devastating (Jones & Weisenfluh, 2003). Filled with existential complexities (Jassal & Sims, 2006; Kane & Primomo, 2001), caring for a dying child and their family can be challenging for staff, requiring a high level of competency (Payne, 2008). Staff also need to ensure they reflect on their own experience and beliefs about bereavement (Chan, Fong, Wong, Tse, Lau, & Chan, 2016) in order to be able to provide "good enough" care (Papadatou, 2006). The need for specialist training for staff has been identified (Mickan & Rogers, 2005; Turner, 2010) leading to worker "hardiness" (Payne, 2008) but challenges can arise if the competency level of the staff member is not appropriate to the care being provided (Hain, Heckford & McCulloch, 2012; Hughes, Firth & Oliviere, 2014; Ryan et al., 2014).

Many of the studies centred on care provided within a PICU or by staff based there as the majority of children's' deaths occur in these units (Davies, Sehring, Partridge, Cooper, Hughes, Philp . . . Kramer, 2008; Howes, 2015). This literature review focuses on highlighting the provision of a quality approach not just to the physical end of life but to the quality of that dying and death experience, which can bring comfort to the child and their family (Sellers, Dawson, Cohen-Bearak, Solomond & Truog, 2015).

In the next section of this chapter, the review of the literature undertaken examining the experience of staff who provide care to children and families is discussed. Three major areas of consideration arose in that process: a) interdisciplinary teamwork; b) working with families at EOLC; and c) impact of children's EOLC on staff.

3.3.1. Interdisciplinary Teamwork

The complexity of EOLC for children and their families requires the appropriate skill sets and competencies in order to optimise this type of care (de Cleyt et al., 2016; Greybill, Esch, Vinoski, Truscott, Torres, Daniel, Crenshaw & Crimmins, 2016; Jassel & Sims, 2006; Mickan & Rogers, 2005). A team made up of all of the relevant disciplines, working together, is an essential element of palliative care work (Alexsson & Alexsson, 2009; Greybill et al., 2016; Himmelstein, 2006; McNeilly & Gilmore, 2009). The traditional multidisciplinary approach (Turner, 2010) has been criticized as being too narrow as it can facilitate disciplines remaining within their professional alliances unaffected or unchanged by the influence of others (Wolfe et al., 2011), requiring the family to take on the burdensome role of being the centre of communication among the team (Friebert, Chraster & Brown, 2011). Approaching care from the perspective of an interdisciplinary team allows for more fluidity and flexibility resulting in team goals that are more aligned with patient need (Fort Cowles, 2003, Jassal & Sims, 2006; McNeilly & Gilmore, 2009; Satbir & Sims, 2006) and in dealing with its complexities (Papadatou et al., 2011; Price & Cairns, 2009; Remke & Schermer, 2012). Wolfe et al. (2011) go further to explain their perspective that, rather than clinicians working in silos, members of the interdisciplinary team collaborate in "overlapping circles" which allow specialties to maintain their identity while working together with others to adopt a joint approach to the care of a child who is dying.

Working successfully together to provide interdisciplinary care for children at the end of their lives requires a close working relationship, with clear working principles and characteristics, good communication and mutual respect (Chan et al., 2016; Mickan and Rogers, 2005; Turner, 2010). A small confident interdisciplinary team meeting face to face on a regular basis to make shared decisions and provide ongoing learning opportunities will facilitate the achievement of good interdisciplinary work (Fort Cowles, 2003; Mickan & Rogers, 2005). In addition, it has been found to decrease rates of stress and burnout, improving staff mental health in that staff feel they have clear goals and direction in their work, supporting an excellent quality of care of the patient (Payne, 2008; Turner, 2010). The complexities inherent in the field of children's palliative care invites

the adaptation of an interdisciplinary approach (Chan et al., 2016) due to the “multiple stakeholders, multifaceted issues, uncertain outcomes, differing opinions, and so on” (Ciemens, Brant, Kersten, Mullette & Dickerson, 2016, p. 768). While accepted as the “gold standard” for CPC (Remke & Schermer, 2012, p. 286), interdisciplinary work can be fraught with multiple challenges including shortage of staff, role confusion, confused communication and staff rivalry (Jassal & Sims 2006, pg. 514). In addition, the critical inclusion of the child and family in the decision-making processes can add to the challenges experienced in implementing good interdisciplinary teamwork in CPC (Greybill et al., 2016; Jones, Parker-Raley, Maxson & Brown, 2011; McNeilly & Gilmore, 2009).

The issue of the composition of the interdisciplinary team generates considerable discussion with consensus that an appropriately qualified and experienced team who can address medical, nursing and psychosocial needs with confidence and clarity is best suited to meeting the needs of the child and their family (Brown & Warr, 2007; Ciemens et al., 2016; European Association of Palliative Care, 2007; Jones, Sampson, Greathouse, Legett, Higgerson & Christie, 2007; Turner, 2010; Wittenberg-Lyles, Parler Oliver, Demirir, & Regehr, 2010). The key role played by support staff ¹⁴within a hospital is also critical to the successful undertaking of children’s EOLC (Swinney, Yin, Lee, Rubin & Anderson, 2007).

3.3.2. Working with Families at End of Life Care

Staff caring for children when there is a decision to move to comfort, rather than active care, need to refocus their approach (Goymour, Heaton, Coombs, Kelk, Estreich, Sarraf, . . . Jaaniste, 2019). Staff need to ensure that the child is kept comfortable and recognise that how that care is provided will impact on the grieving process of those who survive (Falkenburg, Tibboel, Ganzevoort, Gischler & van Dijk, 2018; Howes, 2015; Kongnetiman et al., 2008; Sellers et al., 2015). Key elements of the approach that is required are: excellent communication and relationship building, clear decision making that includes the family; and recognizing and addressing the complexities of this work.

i. Communication and Relationship Building: No team can work effectively in children’s EOLC without good communication skills (Mack, Hilden, Watterson, Moore, Turner, Grier . . . Wolfe, 2005; Marsac et al., 2018; Michelson,

¹⁴ Including catering staff, administrative staff, portering staff etc.

Charleston, Aniciete, Sorce, Fragen, Persell, . . . White, 2020) that are “concise, skilled and effective” (Price & Cairns, 2009, p. 38). Interactions between families and staff requires the delivery of clear messages, in an approach that suits the family’s background (Kongnetiman et al., 2008). “Parents consistently report a need for honest complete information, delivered with sensitivity” (Marsac et al., 2018, p. 862). The process of communication plays a central role in the family experiences of care at EOLC, impacting on the provision of good medical care for the child, and affecting staff “psychological morbidity” (Michelson et al., 2020, p. 271). The use of complex medical terminology, for example, can lead families to believe that the team caring for them do not understand their predicament (McNeilly & Gilmore, 2009) particularly if the family perceive the use of such language as a mark of status or power (Jassal & Sims, 2006). Good communication is particularly critical at times when new information is imparted, such as the introduction of EOLC (Price & Cairns, 2009). Kongnetimen et al’s (2008) identification of the long-term impact that poor communication can have for the family left behind is critical. Staff taking time with families to communicate difficult news can help the preparation for the death, the understanding of the reasons their child is dying, creating some sense of mastery for the family in facing their bereavement. Its absence, however, can serve as a barrier to the provision of the best medical treatment to the patient “including postponing palliative care and continuing invasive, potentially non beneficial treatment” (Rose & Shelton, 2006, p. 5)

The complexities of good communication can be seen in studies that include both parents’ and staff perspectives. In their US-based study of 144 parents whose children received care for terminal cancer, parents were interviewed by telephone (109) or in person (35) and asked to rate various aspects of the care they and their child received using a pre-determined scale (Mack et al., 2005). Mack et al. (2005) found that parents rated highly physicians giving clear information about what to expect when their child was dying, communication that was delivered with care and sensitivity, speaking with the child if appropriate and discussing in advance with parents the likely circumstances around their child’s death. However, the conclusion about the values that parents and staff place on good communication highlight how difficulties may arise.

“For parents of children who die of cancer, doctor-patient communication is the principal determinant of high-quality physician care. In contrast, physicians’ care rating depend on biomedical rather than relational aspects of care” (Mack et al., 2005, p. 9155).

In addition, Falkenburg et al., (2018) found that parents experienced a sense of “connectedness” with staff when interactions went well, while they experienced “estrangement, emotional distancing, and loneliness” when they were difficult (p. 157). Despite the complex nature of communications in children’s EOLC, good interactions can build positive relationships between parents and staff, leading parents to report a sense of being supported through this difficult time (Dos Santos, Szyllit, Deatrlick, Mooney-Doyle, & Wiegand, 2020).

ii. Decision Making in EOLC: An area that staff found particularly difficult in children’s EOLC is dealing with the frequent uncertainty about the outcome for a child and the difficulties in discussing or implementing EOLC¹⁵.

Studies reviewing the medical processes before death, offer percentages of concurrent perspectives between parents and staff, demonstrating the difficulties in getting agreement on the appropriate care plan for children. Some studies report a level of agreement between 50% (Lago et al., 2010) and 60% (Garros, Rosychuk & Cox, 2003) between parents and staff for cessation or withdrawal of active treatment. Factors that contribute to consensus building are: long term relationship with the medical team (Zaal-Schuller et al., 2016); recognition by parents that the life-threatening nature of the illness (Mitchell & Dale, 2015); involvement of a range of health care professionals (Lago et al., 2010; Lotz et al., 2015; Mitchell & Dale, 2015) and planning for implementation of EOLC (Lotz et al., 2015; Jongjai, Chawapornpan, Jutarat, Srimana & Sanit, 2020). The agreement for EOLC requires good communication through regular meetings with families (Garros et al., 2003) and the provision of clear information at the time of the medical crisis (Mitchell & Dale, 2015).

Staff find this area of work particularly challenging, however, because of their own position within the interdisciplinary team or due to their own belief personal belief systems (Lotz et al., 2015; Mitchell & Dale, 2015). At times, this is because staff cannot agree among themselves as to what is the appropriate path forward (Lotz et al., 2015, Mitchell & Dale, 2015). In other situations, they provide care to the child but are not involved in the decision-making (Inghelbrecht et al., 2009; Lago et al., 2010). For others, their personal beliefs placed them into conflict with parents, with the result that they left

¹⁵ (Beckstrand, Rawle, Callister & Mandleco, 2010; Bogetz, Root, Purser & Torkildson, 2019; Davies et al., 2008; Inghelbrecht, Bilsen, Pereth, Ramet & Deliens, 2009; Lago, Nilson, Piva, Vieira, Halal, Abib & Garcia, 2010; Lotz, Jox, Borasio & Fuhrer, 2015; Mitchell & Dale, 2015 Pritchard et al., 2009; Zaal-Schuller et al., 2016)

the decision-making to parents (Akpınar et al., 2009; Inghelbrecht et al., 2009; Jongjai et al., 2020). While many children die quickly after this decision is made (Garros et al., 2003), in some situations the involvement of a qualified facilitator (Lotz et al., 2015) or the legal system (Brierley, Linthicum & Petros, 2013) were required to decide what was in the best interest of the child.

iii. Complex Nature of the Working in Children's EOLC: Interdisciplinary team working in children's EOLC can also be fraught with problems (Ciemins et al., 2016), particularly if the team have experienced little training or guidance in this area (Remke & Schermer, 2012). Many of these challenges come from the nature of the work (Beckstrand et al., 2010; Bogetz et al., 2019; Davies et al., 2008). The majority of child deaths occur in the PICU, where the specialist work is saving children's lives, not facilitating them to die (Jones et al., 2007; Davies et al., 2008). For both families and staff, a "radical cognitive, emotional and spiritual shift" needs to take place to refocus care on a dignified death rather than a cure (Jones et al., 2007, p 54). Difficulties often stem from the differing perspectives of parents and staff caring for the child. The family's beliefs and values can be the antithesis of staff professional beliefs particularly if staff believe that a child is suffering (Verhagen, 2018). The difficulties experienced by staff identified in the literature include: a) ethical issues and b) multicultural practice.

Ethical Issues: Because of the nature of the challenges that present in children's EOLC, dealing with ethical issues, particularly those around when is the appropriate time to cease active treatment, can cause difficulties for all parties involved (Dryden-Palmer, Garros, Meyer, Farrell & Parshuram, 2018; Jones et al., 2008; Kongnetiman et al., 2008; Wiener et al., 2013). While the European Association of Palliative Care ("EAPC") address the ethical and legal rights of children who are dying and provides a useful guideline to staff to ensure there is no "burden without benefit" for the child (EAPC, 2007; Weise, Okun, Carter, Christian & American Academy of Pediatrics, 2017), the complexity of this issue has proven challenging not just for the staff involved but for society in general (Hammond-Browning, 2017). The EAPC outline two "guiding principles" for teams who care for dying children. Firstly, that the "best interest" of the child is placed at the forefront of all care decisions. Secondly, that teams balance "benefits and burdens" of each intervention,

"favoring interventions that are likely to provide greater benefit than burden for the child and discouraging the initiation or continuation of interventions that are likely to lead to greater burden than benefit" (Weise et al., 2017, p. 2).

By giving consideration to the burden aspect of care, as well as the benefits, teams can quickly develop a more balanced approach to the questions of how to proceed and work with the family to explain their concerns about the burdens presented to the child with the persistence of futile treatment (Brierley et al 2013; O'Brien et al., 2010).

Despite such clear guidelines however, agreement between the team and parents about the future care of the child is not always achieved (Jones et al., 2008). This situation can develop into a difference of opinion about a child's care and result in a 'disparity of explanatory frameworks' (Carnavale, 2004). This is due to the different cognitive process for parents, which focus on their connection to the child and the unnaturalness of their death, while staff concentrate on the futility of continuing treatment (Wiener et al., 2013). This can lead to complexities in relation to the ethical and legal issues faced by the team which may mean that the hoped-for approach cannot be provided to the child (Kongnetiman et al., 2008).

The need to recognize the influence of professional values in this work is critical. Often professional values influence the possible pathways of care that are decided on in individual cases (Himmelstein, 2006). Combining different professional values within a team, especially if those professional values are competing can be stressful (Weise et al., 2017), particularly when there is an absence of local and national legal frameworks or professional guidelines (O'Brien et al., 2010, Weise et al., 2017).

Multicultural Practice: The interdisciplinary team needs to take into account the cultural norms and practices of each family they care for at the end of life process as these beliefs influence interactions and decision making (Brierley et al., 2013). Even the definition of "family" can vary among cultures and teams need to appreciate this in order to deal with the family sensitively and appropriately (Wiener et al., 2013).

"When there are cultural gaps between families and health care providers and these gaps are accentuated by barriers of language, faith, and cultural values and beliefs, it becomes all the more difficult to negotiate transitions on the path of a child's death." (Kongnetiman et al., 2008, p. 1)

At times, this can even extend to whether or not the family accept the concept of palliative care, with some dominant world religions not espousing such a concept. For example, in the Islamic faith, suffering, even in children, can be seen to have a "redemptive aspect"

so that when the values of preservation of life and the end of suffering are weighed up “the sanctity of life outweighs quality of life issues” (Hedayat 2006, p. 1282). This can cause complications for parents who may feel that they are going against traditional family beliefs by accepting the suggested best medical course for their child (Wiener et al., 2013). However, it can often take time to establish the influence of such beliefs, leaving staff, particularly in a hospital setting, concerned that they may be imposing more harm on a child by lack of decision making or lack of acceptance of the suggested care plan. This can equally apply to other features of palliative care such as different beliefs about the location of a death, or saying goodbye to a child, or different ways that cultures exhibit their grief (Wiener et al., 2013).

However, making any assumptions about a family’s beliefs because of their ethnic origin can be equally fraught, and teams need to ensure that each family is treated individually as the influence of the dominant culture can be different in different circumstances. “According to health care professionals, staff often assume that all members of an ethnocultural group have the same beliefs and family members similarly described a tendency among staff to generalize by community rather than recognizing a person as a unique individual.” (Kongnetiman et al., 2008, p. 2). This is not a well-developed area of investigation in children’s palliative care.

3.3.3. Impact of Children’s End of Life Care on Staff

Staff caring for children at EOLC experience both a personal and professional cost (Bateman, Dixon & Trozzi, 2012; Dryden-Palmer et al., 2018; McConnell, Scott & Porter, 2016; Muskat, Greenblatt, Anthony, Beaune, Hubley, Newman, . . . Rapoport, 2020). The laudable aspiration of achieving “a good and proper death” (Mu, Tseng, Wang, Chen, Huang, Hsu & Florczak, 2019, p. 19), belies the challenging pathway to achieving such a goal which can be fraught with difficulties between staff (Remke & Schermer, 2012). In a large Canadian quantitative, questionnaire-based research study with 946 health care professionals in a children’s hospital, Archambault-Grenier, Roy-Gagnon, Gauvin, Doucet, Humbert, Stojanovic, . . . Duval (2018) found that 41% of respondents had witnessed or been involved in EOLC discussions. Of that group, 73% reported that these discussions lead to disagreements, of which they believed that almost 60% were among professionals themselves. Areas of conflict revolve around the inconsistency with which EOLC is provided (Basu, 2013), lack of clear care goals (Tubbs-Cooley, Santucci, Kang, Feinstein, Hexem & Feudtner, 2011), the impact of providing what staff perceive

to be “futile” treatment (Brierley et al., 2013; Mahon, Deatrck, McKnight & Mohr, 2000; O’Brien et al., 2010) and the emotional burden on staff of providing care (Mu et al., 2019). While there is a concern that such conflicts can affect team members’ professional functioning, it can allow for robust discussion and decision-making within a team, which can ensure that the team function well together at a high level of collaboration and co-operation (Verhagen, 2018, p. 192).

In addition to the frequent conflicts and demands of EOLC for children, staff must face multiple child deaths which can involve a significant emotional toll (Bateman et al., 2012).

“Health professionals working with the dying child and family draw upon their expertise and experience to engage with children, parents and families on this painful journey. This is a delicate and sensitive area of practice and has strong and penetrating effects on health professionals.” (Forster & Hafiz, 2015, p. 294)

For children’s deaths, staff need to develop both professional coping strategies at an emotional level but also at an existential level in order to provide optimal care (Chan et al., 2016). Therefore, staff support is of critical importance (American Academy of Pediatrics, 2013). Staff need to “intimately understand how to provide EOLC, including an examination of their own experience of the event” (Mu et al., 2019) through training, their own reflection and an institutional recognition of the impact of the death (Holland & Neimeyer, 2005; Rushton, Reder, Hall, Comello, Sellers & Hutton, 2006, Clarke & Quin, 2007). This is particularly critical as teams can, at times, experience a lack of connectedness, reflective of the rupturing process experienced by family members when a loved one dies (Papadatou, 2006).

An individual’s motivation to do this work is also a critical focus for staff. The closeness of the relationships formed with the child and family, and the possibility of making a difference at a very difficult time in their lives provide strong motivation for staff (Brown & Warr, 2007). Papadatou (2006) suggests that staff in EOLC need to develop insight into the “suffering” it causes for them, bringing forth staff vulnerabilities and their own unresolved personal bereavements. This process allows staff to recognise that being vulnerable is part of the work of providing care to children who are dying and their families (Papadatou, 2006). Described by Chan et al (2016) as “death work”, this process of acknowledgement of and reflection on the impact of this work on staff is becoming more recognized (Dryden-Palmer et al., 2018; McConnell et al., 2016; Morgan, 2009).

This “suffering” is described variously within the literature as “compassion fatigue” (Rourke, 2007), “extreme distress” (Brown & Warr, 2007), “personal pain” (Morgan, 2009), “burn-out” (Larson, Dryden-Palmer, Gibbons & Parshuram, 2017) or “moral distress” (Dryden-Palmer et al., 2018). Whatever the term used, this pile up of stressors inherent in providing support to a dying child and their family can result in staff over-responsiveness to everyday stressors, or under-responsiveness in terms of burnout (Dryden-Palmer et al., 2018), particularly if staff have not had the chance to deal with each death and the effects of multiple losses become cumulative (Brown & Warr, 2007). With the demands of busy workplaces and scarce resources, this can become a challenge as “teams become trapped in a vicious cycle of clinical work overload” (Mickan & Rogers, 2005, p. 366). High levels of competency in coping can be achieved through self-reflection and self-care (McConnell et al., 2016) providing staff with the protection they need from becoming overwhelmed, so that the positive rewards of this work and the family appreciation can be recognized by the staff (Payne, 2008).

“It is my belief that the only distance we have power to determine and control is the *distance we choose to maintain from our own selves*. Such distance enables us, first, to recognize the impact that loss and death-related experiences have upon ourselves. Our willingness to turn our gaze inwardly may help us better understand how we invest in our relationships with patients and families, and how we are affected when we remain open and vulnerable.” (Papadatou, 2006, p. 522)

However, the individual alone cannot be responsible for the management of this moral distress (Dryden-Palmer et al., 2018; Payne, 2008; Rushton et al., 2006). Working within an organization that recognized and supports staff to manage these distresses is highly valued by staff (Riotte, Kukora, Keefer & Firn, 2018; Rushton et al., 2006; Rourke, 2007; McConnell et al., 2016). Practices such as structured peer-supported storytelling (MacPherson, 2008) or a structured debrief within 48 hours of the death (Bateman et al., 2012) have been found to be useful. But there is general consensus that a combination of personal reflection, collegiate support, learning and teaching opportunities combined with organisational recognition and support provided staff working in this area can lead to staff recognition of the “compassion satisfaction” to be found in this work (Bateman et al., 2012; Riotte et al., 2018; Rushton et al., 2006; Rourke, 2007).

3.3.4. Role of Social Work in Children's EOLC

Within the initial searches as outlined above, three articles that specifically mentioning the role of social workers were found (Muskat et al., 2017; Muskat et al., 2020; Remke & Schermer, 2012). However, hand searches found further research documenting the experiences of social workers working with dying children and their families which allowed for a somewhat broader review of this area.

Like the families they work with, social workers, too, have their emotional strength challenged when they find themselves in this intimate and sensitive world of a dying child (Robert et al 2012; Vargas & Ostrander, 2012). Developed in the past 20 years (Cadell et al., 2012, Jones, 2012, Remke & Schermer, 2012), the social work role with children and their families at EOLC is both challenging and professionally rewarding (Jones & Weisenfluh, 2003). Because of social worker's role in providing psychosocial support, together with a strong ethical framework, the profession is well placed to support families at this time of their lives (Jones et al., 2007). Filled with existential complexities (Jassal & Sims, 2006; Kane & Primomo, 2001), the social work role encompasses listening and counselling as key support elements of this work (Jones, 2006a). According to Csikai (2004), social workers are particularly equipped to deal with the complex ethical challenges that arise. At times however, the key social work role is to "bear witness" to a death and the family's distress (Vargas & Ostrander 2012).

The positive contribution that social workers make to the very complex work in CPC in PICUs is highlighted (Robert et al., 2012). Because of the fast pace, aggressive and cure focus of a PICU, it requires excellent communication to make the appropriate decisions about the child's care (Rose & Shelton, 2006). "Families value communication above all else when their child is critically ill" (Doorenbos et al., 2012, p. 310) and the excellent communication skills of the social worker allows them to support the family in the very steep learning curve of becoming familiar with the PICU environment (Jones, 2006b). Furthermore, the social worker's skill in facilitating communication through family conferences, allowing for the demystifying of medical language, for example, facilitates the family's understanding of the medical crisis they are facing and allows understanding of the decisions that lie ahead (Doorenbos et al., 2012). Despite its many challenges and the emotional impact it can have, Muskat et al. (2017) found that social workers spoke of their work as a "privilege", and were grateful to be involved in families' lives and provide support to them.

“It is because of the tremendous vulnerability of dying children and their families that the profession of social work is so uniquely situated to be of assistance. This vulnerable position often creates ethical dilemmas in a hospital setting where families may feel disempowered or intimidated and therefore unable to advocate for their own unique needs and wishes. Social work values of self-determination, empowerment, and starting where the client is all speak to the important ethics of giving primacy to child and family in end-of-life decision-making.” (Jones, 2006b, p. 59)

As can be seen from the literature, the social worker is an essential part of interdisciplinary teamwork in children’s EOLC and their professional skills, values and beliefs equip them well to support families during this very difficult experience.

In this section, I have reviewed the working of the interdisciplinary team at EOLC for children. While guidelines and lessons learned from adult palliative care can help to guide and support teams working in this area, the work of teams with children who are dying and their families’ needs further exploration (Sellers et al., 2015). The dilemmas, challenges and professional and personal resources required to do this work have been explored, and the complexities arising from this work have been identified. Perhaps it is Papadatou’s (2006) belief in the central role of reflexivity that will nurture and sustain both individuals and teams in this work. Even when legal and good ethical frameworks are in place to guide work in children’s EOLC, reflection by the interdisciplinary team on each child’s situation is critical, as described by this doctor:

“As we develop the legal and ethical systems to help doctors and families with ... decisions, we should continue to strive for meticulous attention to the interests of our patients, transparency about our practices, and honesty with ourselves about our distinctions, our methods, and our goals.” (John D. Lantos interviewed in de Cléty et al., 2016, p. 5)

3.4 Conclusion

This chapter has summarized the findings from literature reviews undertaken examining the experience of parents and staff at children’s EOLC. The chapter provided a detailed review of the literature on parents’ experience of EOLC, highlighting the life-altering nature of this experience for parents and discussing their needs. The research findings show the potential serious long-term implications for parents in terms of their physical

and mental health and the impact on social factors including employment and earning potential. Three emerging findings within the literature were addressed including parents' feedback on being involved in research, their particular view of hope within EOLC, and the findings on the potential for post-traumatic growth among bereaved parents. For staff, the need for close interdisciplinary teamwork and paying attention to parents' needs were highlighted. The need for staff to treat each family as an individual unit with a belief and value system that influences reflects their approach and behavior within EOLC was highlighted. The growing literature in relation to the impact of this work on staff was also discussed.

CHAPTER 4: METHODODOLOGY

In earlier chapters, the basis of this research and the experiences of those who are participants was described. Throughout this work, the complexity of this type of death for parents and for the staff who work with them has been emphasised. This required the researcher to be respectful and mindful of these sensitivities and vulnerabilities when carrying out research in this area, at the same time as ensuring that the voices of families who lose a child, and those who work with them, are captured and spoken about. It is with these factors in mind that I approached the development of the methodology to be used in this research.

4.1. Research Paradigm

The purpose of undertaking research is to seek out new knowledge and to seek answers to questions using a clear conceptual framework of philosophical ideas, known as the research paradigm (Hickson, 2016). This paradigm informs the research and fits its purpose, drawing together a strong foundation for the research (Bryman, 2012; Maxwell, 2008; Rubin & Rubin 2012; Thompson,1992). It provides a

“set of assumptions concerning reality (ontology), knowledge of that reality (epistemology), and the particular ways of knowing about that reality (methodology)” (Crabtree & Miller, 1999, p. 8).

Within each paradigm, a view of the world is assumed, describing how people are in the world, how the world is organized and how knowledge is constructed within that world (Thompson, 1992). In this section, I describe the research paradigm chosen for this work.

4.1.1. Qualitative Approach

Due to the nature of this study, a qualitative approach was adopted, emphasising the conceptual rather than the logical level of the research (Davidsen, 2013). Qualitative research provides an opportunity to examine the particular nature of the phenomenon under examination, in contrast to the alternative quantitative approach to research which focuses on dominant trends (Hyvarinen, 2008). Qualitative research, by definition, does not have a single, identifiable approach, nor does it come with prescribed procedures (Crabtree & Miller, 1999; Maxwell, 2008). Research using this approach is defined as a

set of practices surrounding the research (Denzin & Lincoln, 2008). It does not seek out general laws but emphasizes interpretation as an ongoing activity within each person's environment and specific context (Bryman, 2008; Hickson, 2016). The goal of qualitative research is to explore everyday phenomena seeking out differences in meanings and perceptions (Crabtree & Miller, 1999, p. 6).

When undertaking research, the researcher's approach is regulated by their own perspective on the nature of the social world, their beliefs about how knowledge is created, and the nature and setting of those who will participate in the research (Ormston, Spencer, Barnard, & Snape, 2014). Equally, the researcher can look to their own set of skills and experiences to inform the research methodology (Crabtree & Miller, 1999). Adopting a qualitative approach to research is an appropriate fit for social work research, in that it is designed to capture the voices of people who experience challenging and demanding social situations. In addition, by prefacing the voices of research participants, a qualitative approach ensures that their particular social challenges are heard (Hardwick & Worsley, 2016).

Whatever the researcher's background, a clear and transparent delineation of the approach to be taken within the research is critical (Drisko, 2013a). The framework for the approach to this research is set out below.

4.1.2. Ontology

As outlined in Chapter 2, an ontological approach of social constructionism has been adopted within this research. A social constructionist approach "inquires after the social conventions, perception, and knowledge in everyday life" (Flick, 2009, p. 69). This approach espouses the view that there is no single reality or truth, and that individuals will construct their reality based on their context (Lincoln, Lynham, & Guba, 2011). Individuals are perceived as learners in social situations and experiences, where knowledge and meaning can be constructed within social groups (Drisko 2013b, Moen, 2006).

Adopting a social constructionist stance within the research setting allows the researcher to hold a position of curiosity and co-evolution with the participants (Crabtree & Miller, 1999). It "emphasises the subjective interrelationship between the researcher and participant, and the co-construction of meaning" (Mills, Bonner, & Francis, 2006, p. 26). Researchers continually search beyond the surface, exploring and questioning the

meaning of the data. Riessman (2013) reflects that those working from a social constructionist perspective take a different approach to the truth:

“Verification of the “facts” of lives is less salient than understanding the changing meaning of events for the individuals involved, and how these, in turn, are located in history and culture.” (Riessman, 2013, p. 182)

Further, the researcher will not impose her interpretation on the contributions of the participants, rather co-create with them a deep knowledge about their experience. Padgett (2009) refers to this as creating a “voice” rather than a set of quotations. In this research, therefore, the approach will be to interpret the reality of bereaved families and the staff who care for them, rather than reach a definition of that reality.

4.1.3. Epistemology

Social scientists’ broad philosophical beliefs about research encompass a standpoint that values multiple approaches to the study of social phenomena (Bryman, 2012; Silverman, 2013). Social constructionists question the applicability of a more traditional attitude encompassed in the positivist approach which seeks a single “truth” (Bryman, 2012) and “treats ‘social facts’ as existing independently of the activities of both participants and researchers” (Silverman, 2013, p. 86). This positivist approach foregrounds objective truths found through research. For social scientists who adopt this approach, they believe that research within this field can be carried out in a similar way to the approaches taken within the traditional sciences, so that facts can be gathered using rigour and objectivity (Thompson, 1992). Kearney (1994) criticises this approach, concerned that it risks a very narrow search for objective facts and invites the researcher to take a much broader perspective (p. 2). Rather than focusing on research that seeks one universal explanation for reality, an interpretivist approach “tend[s] to live with, even celebrate, the possibility of *multiple realities*” (Denscombe, 2014, pg. 97).

Interpretivism is also referred to as the hermeneutic approach. With its roots in an anti-positivism stance, interpretivism places emphasis on the understanding of the other. It is the “recreation in the mind of the scholar ... the thoughts and feelings and motivations of the objects of his study” which Kolakowski sees as an empathy for the subject of the study (1993, p. 11). Perhaps interpretivism is best described by Denzin & Lincoln (2002) who view it as a research approach that positions the researcher as a “bricoleur”.

Referring to the French term for one who creates quilts, he suggests that “the interpretive Bricoleur understands that research is an interactive process shaped by the personal history, biography, gender, social class, race and ethnicity of the people in the setting” (Denzin & Lincoln, 2002, p. 85). Elaborating on this theme of the researcher as a ‘quilt maker’, Shaw and Holland (2014) describe how the researcher “stitches, edits, and puts slices together to create a kind of unity” which allows for different voices, different perspectives, different positions and different stories to be woven into one large whole (p. 206).

In order to support the approach of foregrounding the voice of the research participants, an *inductive* approach was adapted within this work. This inductive process allows the researcher to use the gathered data to consider and develop theory, rather than approaching this research from a single theory or truth (Braun & Clark, 2012; Carey, 2012). In addition, the use of *triangulation* was employed to add richness and depth to the research (Denzin & Lincoln, 2002). Gathering data from multiple sources through interviews with parents and staff, as well as multiple approaches through review, analysis and member-checking and triangulation allowed for multiple perspectives from which to draw conclusions about the findings (Carey, 2012; Denzin & Lincoln, 2002; Drisko, 2013b).

4.2. Methodology

In a piece of research of this nature, a clear methodology for the study is critical (Silverman, 2013). Methodology, according to Carey (2012) “refers to the set of ideas, theory or philosophy that surrounds, encompasses and, literally, ‘holds together’ a research project” (p. 83). An approach that is appropriate to the phenomena that the researcher will be studying is essential (Ormston et al., 2014), while taking into account that in recent years there is less distinction between methodologies (Fortune, Reid, & Miller, 2013; Lincoln et al 2011; Maxwell, 2008). Attention to the need for fluidity and change throughout the research process is required as the research process is “...full of false starts, blind alleys, mistakes, and enforced changes to research plans” (Bryman, 2012, p.15).

This study was undertaken in the broad school of interpretive theory or what is known as hermeneutics. This type of study sets out to understand how people comprehend their social experiences (Carey, 2012). Interpretive theory supports the concept that there

are multiple truths. It further recognises the complexities of the influence of the researcher's experiences and the context of the research on the research outcomes (Krysik & Finn, 2013). It is therefore well suited to this research which was undertaken from the perspective of a practitioner researcher undertaking research in her own place of work. Charalambous, Papadopoulos, & Beadsmoore (2008) report that the hermeneutics approach is particularly suited to the health sciences in that it "supports an approach to health research which focuses on meaning and understanding in context" (p. 637). A hermeneutic approach suggests that objective meanings cannot be imposed on social phenomena (Thompson, 1992), but rather that meanings evolve from the data gathered during research process.

4.2.1. The Interpretive Theory of Paul Ricoeur

In order to explore the origins of the interpretative or hermeneutic approach, I explored the writings of French Philosopher, Paul Ricoeur (1913-2005) whose work is essential to the development of the narrative approach in research (Moen, 2006; Squire, 2008). In his early works, Ricoeur was influenced by and contributed to the school of German Phenomenologists, whose philosophical approach espoused the notion of multiple truths (Moran, 2002; Davidsen, 2013), supporting the concept that knowledge is not fixed but "interpreted through layers of meaning" (Thompson, 2016, p. 212). It allows the experience of research participants to be foregrounded in the research field (Kearney, 1994) facilitating the meaning of lived experiences to come to the fore (Moran, 2002).

One of key strands of Ricoeur's perspective on phenomenology is his divergence from earlier Husserlian thinking about interpretation or hermeneutics (Ricoeur, 2002; Kearney & Rainwater, 1996; Moran, 2002; Bell, 2011). Ricoeur highlighted the importance of an understanding of hermeneutics from its Greek origins where a meaning or interpretation is suggested rather than definitive (Kearney, 1994). Ricoeur (2002) believed that the fullness of experience could be vocalised and that the interpretation of the vocalisation would reflect the expression of such an experience (Bell, 2011). Ricoeur's hermeneutic approach allows the researcher access to the indirect, and truer, meaning within the text (Kearney, 1994). According to Ricoeur (1991),

"It must be supposed that experience, in all its fullness ... has an expressibility in principle. Experience can be said, it demands to be said. To bring it to language is not to change it into something else, but, in articulating and developing it, to make it become itself" (p. 39).

Indeed, Ricoeur believed that the telling of stories could help to reorganise the individual's world, which has been rendered into disarray by trauma or suffering (Devisch et al., 2017).

For Ricoeur (1973) then, the interpretation of the text created through the transcription of the spoken word needed a process or 'Arc' to ensure that the interpreter reflected the fullness of the development of the narrative. This arc is the movement from spoken word to the creation of a fixed representation of the spoken work within a text (Dowling, 2011). This process acknowledges the development of the narrative from the event that is being narrated, through to the creation of the text about the event, and finally to the reading or interpreting of the story within the context in which it is being read (Moen, 2006). Ricoeur proposed a process or 'Arc' for this interpretation that would capture the different features of the experience based on the Greek concept of Mimesis (meaning "imitation" or "representation") (Dowling, 2011). This three-stage process Mimesis1 (Prefiguration), Mimesis2 (Configuration) and Mimesis3 (Refiguration) allows the full complexity of the text to be viewed (Charalambous et al, 2008; Ricoeur, 1984). Missel & Birkelund (2011) provide further explanation of these concepts explaining that Mimesis1 is the "spontaneous understanding" of the story; that Mimesis2 is the transcription of the spoken word into written word; and that Mimesis3 represents the intersecting of the readers world with that of the text.

Ricoeur (1984) strongly advocated that it is only with this analysis of any text that the true meanings contained therein could be revealed, not through the "intentions of the narrator" but by being "opened up by the text's elusive meaning" (Charalambous et al, 2008, p. 638). Flick (2009) reports that the use of this process in the social sciences can allow the researcher to understand the relationship between the story of the event, the impact of gathering that story and creating it into a text, and the impact and influences on the interpretation of that story (Moen, 2006). "Mimesis includes the passage from pre-understanding to interpretation. The process is executed in the act of construction and interpretation as well as in the act of understanding" (Flick, 2009, p. 80).

4.2.2. Practical Field Considerations in Narrative Inquiry

This section explores the issues to be taken into consideration by the narrative researcher during the collection of data in the field in order to create ethically produced

texts. Clandinin (2007), in his discussion of the different approaches to narrative inquiry, suggests two different types of approach. As the first approach suggested by Clandinin (2007) involves the examination of only a small amount of data, it was rejected, due to concerns about the commitments made to all research participants to include their stories. Rather, Clandinin's (2007) second approach in which the inquirer collects the data and it is analysed for "common themes, metaphors, plotlines, and so on to identify general themes or concepts" was adopted as it is more appropriate to the aims of this research (p. xiv). Within this approach, a three-dimensional space for narrative inquiry (Clandinin & Connelly, 2000) was created as an interpretative framing of the analysis. This frame "reveals place, time, motivation and the actor's symbolic system of orientations" (Jovchelovitch & Bauer, 2000. p. 58). While Clandinin & Connelly (2000) acknowledge the complexities of undertaking this task, as it involves the exploration of a broad breath of data, it provides the inquirer with a deeper understanding of the relationship between human actions and their social context (Moen, 2006). I believed that such an approach could encompass all of the stories told within the individual interviews and focus groups collected during the fieldwork of this study.

However, following the first reading and examination of the data using Reflective Thematic analysis, a further narrative reading of the parents' stories then took place, prompted by parents identifying stories that were coded as "having a lovely time" with their child as they were dying. These stories first came to the fore from the texts of interviews with parents' whose child died at home. However, on further examination of the other texts, and in reflecting on the researcher memos written immediately after each interview and after the reading of each transcript, I found that these types of stories appeared in each of the texts of the parents' interviews and contained significant memories for the parents. These stories also appeared to bring comfort to the parents as they remembered them and were often told with very mixed emotions. I then returned to Clandinin's (2007) stance that it is appropriate to examine small parts of the data collected, if they appear significant. I then analysed these stories using concepts drawn from narrative practice in order to explore their full meaning within the research. Ricoeur's (1971) concept of "vouloir dire", or wish to say, was a particularly appropriate approach to adapt in order to extrapolate the full meaning of these stories for parent participants and, in turn, for the staff who had provided care to their children.

Adopting a narrative approach requires careful handling and interpretation of the texts with the following issues needing to be kept under consideration by the researcher:

i. Production of Written Texts: Within narrative inquiry, careful attention is paid to the process of creating texts from the participant interviews (Dreyer & Pederson, 2009; Ricoeur, 1973). Such processing or transcription starts the process of interpretation in that it creates nuanced differences from the original intention of the storyteller, and cannot capture all of the myriad of communication, for example non-verbal communication or a tone of voice (Larsson & Sjoblom, 2010). It does however “help fill in the richness, nuance, and complexity of the landscape, returning the reflecting researcher to a richer, more complex, and puzzling landscape than memory alone is likely to construct.” (Clandinin & Connolly 2000, p. 83). Careful attention has been paid therefore through this inquiry to the process of transcription with interviews transcribed by the researcher verbatim. The development of the written text through transcription is a representation of the collaboration between storyteller and listener and is a vital part of the interpretive process (Moen, 2006). Riessman and Quinney (2005) argue that with “analytic attention” to the sequence of the story, the purpose of the story, its cultural context, as well as attention to what is not present in the story and why, a researcher can find an appropriate approach, the “how and why events are storied” (pg. 394). Such an approach can bring forth stories that are complex and often undervalued due to their complexity (Squire et al., 2013) as well as stories resulting from life disruptions (Jirek, 2017).

It should be noted that within this research, all of the quotes from research participants are transcribed verbatim, including participants whose first language is not English. No corrections were made to the transcript to ensure I reflected the language chosen by participants, including what might be perceived as incorrect use of language or grammar and the employment of colloquialisms.

ii. Being Respectful to Participants: It is critical that researchers adopt a reflexive approach to the creation of the text through transcription and the researcher’s role in that process (Hickson, 2016). They need to recognise the limitations of the participants story – that the story told in research might be a different story than told in a different context as the participants will “chose to present themselves in a particular way to a researcher (Hardwick & Worsley, 2011; Larsson & Sjoblom, 2010). When researching sensitive topics, as with bereavement, where participants may become emotional in the telling of the story, recognition of this as part of their mourning process is essential (Devisch et al, 2017; Dreyer & Pederson, 2009). Attention to the intertwined nature of the relationship between the researcher and participants of the study is critical. Researchers should not be seen as “disembodied recorders” within the interviews as

they need to recognise their own experiences within this process (Clandinin & Connolly, 2000, p. 81). Researchers can be impacted by the emotions attached to the telling of the story and need to reflect on what meaning this might have within the fieldwork (Dickson-Swift, James, Kippen, & Liamputtong, 2009). However, inviting the participants' reflections on the findings from the texts at a later point in the research can create another layer of reflexivity within the process (Larsson & Sjoblom, 2010, p. 279).

It was within this frame of respect for the research participants, their background and culture that an issue around the use of pseudonyms came to the fore. Following a debate about their use, I made an active decision not to provide pseudonyms for the research participants for two reasons. Firstly, I was concerned that choosing pseudonyms for each participant I would be unable to reflect their ethnic or cultural background, which could be perceived to be disrespectful of this important part of their lives. Secondly, the total number of research participants is 39 and so the management of such a large number of pseudonyms would distract from its purpose. I would also hope that, by not using pseudonyms, the reader's attention is centred on the words of the participants and their critical contribution to this research.

iii. Research Reliability: Any narrative inquirer needs to ensure that their research claims are supported by evidence (Chase, 2013, p. 63) and in order to ensure what Hardwick and Worsley (2011) refer to as representativeness, reliability and validity. A number of researchers have provided helpful guides for narrative inquirers in order to create research that is close to the principles of good narrative research (Hardwick & Worsley 2011; Larsson & Sjoblom, 2010; Shaw & Holland, 2014), or "a good enough research strategy" as Riessman and Quinney (2005) suggest. These authors place an emphasis on the importance of:

- A rich systematic data collection system that includes detailed, reliable transcription of interviews;
- A system of analysis that focuses on sequence and consequence as meaningful;
- Highlighting similarities and differences between participant stories;
- An approach that places an emphasis on context (participants contexts as well as research context, relationship and institutional contexts).

(Hardwick & Worsley, 2011; Larsson & Sjoblom, 2010; Riessman & Quinney, 2005; Shaw & Holland, 2014).

As a researcher I am confident that all of these requirements have been embodied within the framework of this study.

iv. Ethical Attitude in Narrative Research: Adapting an ethical approach and having an ethical attitude in all aspects of the study are critical (Chase, 2013; Josselson, 2007), from the planning, to the field work, to the writing up and sharing of the findings with research participants as well as a wider audience. The detailed, ethical structure created for this research to protect participants and their input, is outlined in a 4.4. of this Chapter. This framework has served the research process well and had been actively used by myself as the narrative inquirer to guide challenging and difficult aspects of the research, rather than as a “Trojan Horse” as Squire (2008) suggests simply providing an appearance of ensuring safety to the research participants.

4.2.3. Interpretation-Analytic Considerations in Narrative Inquiry

Once the development of ethically created texts is complete, the inquirer attends to the complexities in interpreting that data (Bold, 2012; Clandinin, 2018; Hickson, 2016; Larsson & Sjoblom, 2010). According to Flick (2004) using a narrative approach to the analysis of texts allows for the interpretation within the context of the narrative and the reintroduction of such interpretations into everyday life which he calls the “mimetic transformation process” (pg 92). This allows us to understand the past and provides a direction going forward (Hardwick, 2017), moving from “story telling” to “a scientific methodology” (Rosenthal & Fisher-Rosenthal, 2004, p. 259).

However, finding an approach to interpretation within narrative inquiry is not automatic (Hyvarinen, 2008; Squire, 2008) and the researcher needs to find an analytic methodology that fits with the purpose of the research (Bold, 2012). Hyvarinen (2008) also highlights the dilemma posed for the narrative inquirer, who needs to find an analytic approach that allows for the analysis to be seen within the broader context of the social, cultural and political world. Therefore, finding an approach that would allow for “thick” descriptions that highlight the interconnectedness of social relationships was critical in

the decision around the analytic narrative approach to be adapted for this study (Moen, 2006).

Following the transcription of the texts, I navigated some of the “tensions” that are characteristic of narrative inquiry (Clandinin, 2007). As a researcher, managing these tensions took the form of a debate around the most appropriate approach to analysis of the data, in order to find a methodology that was inclusive of all of the data collected. I made the decision to use a thematic analysis approach (Braun & Clarke, 2006) in order to be respectful of the breath of stories I had been told. Thematic analysis in narrative inquiry facilitates the categorisation of the data to create larger thematic groupings, providing a structure from which to evolve a broader understanding of the data (Bold, 2012; Hickson, 2016). This allows for the creation of “order from chaos” with the purpose of managing and understanding the data (Hardwick & Worsley 2011, p. 114). This approach reflects the more recent development within narrative research to focus on the context of the stories told, not just their content (Hyvarinen, 2008). According to Squire 2008:

“Narrative analysis also pays attention to the *context* of storytelling: to the real and assumed audiences of narratives, their microcontextual co-construction between tellers and hearers (Mishler, 1986), and to narratives' broader ecological and fantasy contexts. Other qualitative research is of course often reflexive about contextual processes, but such considerations are embedded in narrative work: the notion of 'story' always entails 'audience' as well as 'storyteller'.” (Squire, 2008, p. 7-8)

However, such an approach also allows for the search for difference within the data, reflecting the “detail and particularity” that is so central to narrative inquiry (Riessman & Speedy, 2007, p. 435). According to Hyvarinen (2008) this approach is characterised by a narrative retelling of the story so that its meaning can be understood by a wider audience. My purpose in the process of re-telling the stories of the research participants through the use of a thematic analysis was to manage, understand and find meaning within the data to ensure that these stories can be shared with audiences to influence practice at children’s EOLC going forward.

The use of thematic analysis within narrative inquiry involves the researcher working inductively to seek out emergent themes from the stories told and the hermeneutic interpretation of the relationship between the story tellers and their surrounding context (Ross & Green, 2011). This approach was particularly useful in this study as it been

found to be appropriate for the interpretation of texts from both individual interviews and focus groups in examining how meaning is built up between the participants (Bold, 2012). While some researchers have been critical of the use of this approach within narrative inquiry (Riessman & Speedy, 2007), there is an acknowledgement of its usefulness when applied to stories from clinical practice (Lainson, Braun & Clarke, 2019; Riessman, 2008), particularly in health care research (Sools, 2013; Lainson, 2020). As a result, I am confident that the chosen approach of narrative thematic analysis is appropriate to ensure that the findings from the research are in keeping with the key tenants of narrative inquiry (Chase, 2013) and with the “hopes and aims” of this research (Lainson, et al., 2019).

4.2.4 Challenges experienced using Narrative Methodology

The adoption of a narrative methodology was not without its challenges. During the study, two issues arose in relation to the use of a narrative interview structure, which was intended to allow participants to tell their own story in an uninterrupted fashion. The first was ensuring that the participant understood what they were being invited to do and talk about. This approach had been flagged to participants in the “Participant Information Sheet”, and I had the generative question printed out for each participant to refer to during the interview. However, for a small number of participants, it did take some time, and gentle encouragement through repeating the question, for them to commence their story. As an interviewer, I found it was important not to rush participants, and to reassure them that I had unlimited time to listen. The second issue that arose was the management of the emotions that naturally came to the fore while the participants told their stories. An unstructured approach, with no limits, meant that participants were free to speak about all aspects of their child’s death, including those connected to deep emotions. As a trained clinician, it was challenging not to engage in a therapeutic dialogue with the participant and instead to ensure that a focus on exploration and clarification of experiences, meaning and emotions was maintained without in any way seeking to change or ameliorate perceptions during the interview process. It was, therefore, helpful to bear in mind or clarify when needed, that the emotions contained in recounting their stories were part of parents’ bereavement process, and not distress at being involved in the research process (Dervisch et al., 2017; Dreyer & Pederson, 2009). This necessitated the adaptation of my clinical interview skills in order to conduct narrative research interviews. I realised following memo writing after my first two interviews and through the transcription and review of my own participation in those interviews, that I needed to place more emphasis on my

role as a researcher, ensuring that I desisted from intervening therapeutically, as I was more used to. Being aware that my interventions could influence what the participants chose to talk about or not talk about encouraged me to minimise any intervention thus allowing the narrative to take precedent over the therapeutic potential of the interview. Reflecting with parents at the end of each interview on their experiences of participating in the research allowed me to appreciate that the telling of their experience in detail and without interruption, as part of the research process, was in itself therapeutic for many participants.

4.3. Research Methods

In this section, the research methods chosen to undertake this study will be described in detail.

4.3.1. Research Instrument – Narrative Interview/ Focus Groups

The narrative interview was the chosen method for this study. The narrative interview encompasses a framework that encourages the interviewee “to tell a story about some significant event in their life and social context” (Jovchelovitch & Bauer, 2000, p. 59). Its objective is to gain information from the participant as directly as possible with minimal involvement of the interviewer (Missel & Birkelund, 2011, p. 297). Within the interview the researcher is facilitating the story to be told in full, from the beginning, to the middle to the end (Hyvarinen, 2008). The researcher poses a single key question at the beginning of the interview, allowing the interviewee to introduce parts of the story that are significant to them during the course of the storytelling (Missel & Birkelund, 2011). This key question, known as the “generative narrative question” carries with it the expectation that the interviewee will provide a full and uninterrupted “story” or narrative (Flick, 2009). The interviewer will know that this part of the interview has come to an end when the interviewee introduces a ‘coda’ or indication that the story is complete (Svasek & Markieta, 2013). Following this part of the interview, the second part of the interview explores topics raised by the interviewee which require further expansion or explanation through researcher questioning (Flick, 2009). This step in the interview allows the researcher to explore in more detail issues raised during the narrative. It is critical that the researcher does not introduce questions about issues of interest to the researcher (exmanent questions) but asks about “themes, topics and accounts of events that appear

during the narration by the informant” (immanent questions) (Jovchelovitch & Bauer, 2000, p. 62). This is to again gather more detail from the interviewee’s perspective, reinforcing the idea that interviewees are experts in their own lives and experiences (Flick, 2009). The structure of the interview allows for this story to come forth by moving away from imposed questions from the researcher (Jovchelovitch & Bauer, 2000). By using this structure, the interviewer can minimise their impact on the interview so that the story that is forthcoming allows for the purest recounting of the event from the interviewee’s perspective. This reinforces the interviewer’s role as “a listener, abstaining from interruptions, occasionally posing questions for clarification, and assisting the interviewee in continuing to tell his or her story” (Kvale & Brinkmann, 2009, p. 155). A copy of the interview structure can be found at Appendix 3.

The structure for staff focus groups reflected the structure used for the individual parent interviews. I chose to use focus groups in interviewing the staff as it allowed for the eliciting of individual staff stories of caring for a child who has died, as well as the exploration of issues that are important to the research participants as a group (Kitzinger, 1995). At the start of each focus group, I explained the process of listening to each participants’ chosen story of working with a family whose child was dying, and each of the groups respected this process without further prompting from myself. The process of the group listening carefully to each member’s individual contribution gave rise to rich group discussion and exchange which is seen as a key function of focus groups (Ansay, Perkins, & Nelson, 2004). In addition, focus groups allow for the identification of questions and concerns arising from the exchange between participants within the group (Bloor, Frankland, Thomas, & Robson, 2001). In this study, discussions of concern to for group members, such as the challenges of undertaking EOLC, or the position of siblings in the end of life process, evolved naturally within the group discussion. The combination of the individual stories told by each participant and group discussion allowed the narrative intention of exploring different levels of meaning within the staff contribution during the focus groups to emerge (Thompson, 2016).

4.3.2. Access and Recruitment

In this study, a purposive sampling approach was adopted, which is found to be particularly suitable when undertaking qualitative research so that cases that provide an in-depth insight into the research subject are identified for recruitment (Devers & Frankel, 2000). Researchers need to seek cases that provide typical examples of the topic being researched as well as minority cases that would provide examples of an unusual or exceptional aspect of the phenomena, so that rich information on the topic being studied can be sought (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015)

i. Characteristics of the Children who Died: To reflect the composition of the causes of death of children cared for by the hospital, families whose child had died from the following causes were invited to be involved with the research¹⁶:

- families whose children die from a life-limiting condition either in hospital or at home in a planned or unexpected way,
- families whose children died from an acute onset illness and died in the hospital; and
- families whose child died as the result of a trauma (road traffic accident, accident in the home)

The table below sets out the characteristics of the children who died and whose parents took part in this study:

Age at time of death	<i>Under 1</i>	<i>Age 2-5</i>	<i>Age 6-10</i>	<i>Age 11-16</i>
	1	6	1	4
Child's Gender	<i>Male</i>		<i>Female</i>	
	6		6	
Cause of Death	<i>Life Limiting Condition</i>	<i>Sudden (Trauma)</i>		<i>Sudden On-Set Illness</i>
	7	3		2
Place of Death	<i>Hospital</i>		<i>Home (Planned)</i>	<i>Home (Unexpected)</i>
	9		2	1
Time between death and interview	<i>6-12 months</i>	<i>1 year to 18 months</i>	<i>18 months to two years</i>	<i>Two years to two and a half years</i>
	1	3	6	2

Table 5: *Child Characteristics – Number = 12*

Some particular demographics are of note:

- The ages of the children whose lives are represented in this study are higher than would be representative of the overall profile of children who die in Ireland

¹⁶ Access was provided to the researcher by the research site to information in relation to the cause of death of all hospital patients who died during the study period.

annually (see Table 1). This is because the study took place in a paediatric hospital that does not have a maternity component. Perhaps too it could be speculated that the fact that parents who had longer time with their children might be more motivated by the research participation's "legacy building" function (Moxley-Haegert, 2015).

- In examining the cause of death, a broad spectrum of all three categories of illness is covered, with a dominance of parents whose children had life limiting condition. As part the ethical approval received from the research site, I was able to access information of the overall causes of death for patients of the hospital per year from 2017-2019 period and this sample is representative of the types of deaths that occur among hospital patients during that period.
- In relation to the location of death, three of the children in the study died in their own home. Two of these children returned home following hospitalisation in the site hospital for a short, defined period of care, with death at home being an active choice for parents. For the third child, while they too had a life limiting condition and active involvement from the community palliative care team, this parent would describe their child's death as sudden and unexpected.

ii. Characteristics of the Parents who Participated in the Research: Families were recruited for this research by members of the medical social work team ("social workers") who acted as gatekeepers. Inclusion and exclusion criteria for all parent participants are set out below:

Inclusion Criteria
<ul style="list-style-type: none"> - 6 months to 2 years post bereavement, with the provision that a family who agrees to be involved with the research but are not ready to do so until outside of this timeframe will be facilitated, if possible; - Families will have had a child who has been provided EOLC by the hospital, and has died, regardless of the location of death; - The cause of death will be inclusive so that families whose child has died of an accident, SUDI, sudden onset acute illness or were born with or developed a life limiting condition will be eligible to be included; - Be sufficiently fluent in English so that the gatekeeper and interviewer can be satisfied that their experience and perspective can be fully understood, and that their language capabilities do not diminish the ability to capture that perspective; - Parents should be 18 years old or over; - Can be parents of other living children or not; - Parents are invited from a broad background of nationalities, cultures, religions and life experiences.
Exclusion Criteria
<ul style="list-style-type: none"> - Parent who may attribute the cause of their child's death to the site hospital; - Parents whose child had died where the Child Protection services were involved before or after the death; - Parents where the researcher has been the primary provider of psychosocial support during EOLC and bereavement; - Parents with an active psychiatric condition or additional current social challenges; - Any parent whom the social work gatekeeper or researcher believed could be adversely affected by participating in the research.

Table 6: Inclusion and Exclusion Criteria for Recruitment - Parents

Following an introductory presentation about the research to the Medical Social Work team, social workers were invited to express interest in being a gatekeeper. A Gatekeeper Information Sheet (See Appendix 4) and a recruitment protocol were sent via email to the gatekeepers. Once the gatekeeper identified a possible family to invite to participate, a discussion took place between the gatekeeper and myself to ensure that the family fitted within the inclusion criteria for the study and that no factors in their history suggested exclusion. The gatekeeper then followed the Recruitment Protocol by contacting the family and providing them with a copy of the Participant Information Sheet-Parents (see Appendix 5) and providing them with a two-week period to consider participation. At the end of this period, the family were again contacted by the gatekeeper to garner their interest in participating in the study. The gatekeeper then emailed the researcher when a family had confirmed they would be willing to participate in the study or confirming they thanked them for their time in considering participation, if they chose

not to be involved. The email confirming a family's participation included demographic information about the family and their preferred method/ timeframe for contact by myself. I then contacted the key contact person within the family by telephone within their preferred timeframe to again review the Participant Information Leaflet-Sheet (Appendix 5) and answer any questions about the study. A date for the research interview was arranged at their preferred location (home or at the research site). I contacted all participants again 24 hours prior to the date for the interview to confirm that the planned date and time continued to suit them and to ensure that proceeding with the interview was not overly burdensome for them at this time.

For most parents, a short period (approximately one to two months) elapsed between the time of recruitment to the study and the interview taking place. However, in the case of two families, a request was made to wait some time before interview, due to other circumstances that were occurring in the family during that time. For other families, short delays occurred because potential interview dates were near to the child's birthday or anniversary. In addition, no interviews took place in December or January of the field work period in order to avoid the emotionally sensitive Christmas period.

A total of 12 interviews were completed with 15 parents (three couples chose to be interviewed together). In the chart below a brief demographic of the parent participants is outlined:

Age	<i>Range</i>	<i>Mean</i>	<i>Median</i>	
	31-54	39.9	40	
Gender	<i>Female</i>		<i>Male</i>	
	10		5	
Marital Status	<i>Married</i>	<i>Separated</i>	<i>Single Parent</i>	
	13	1	1	
Nationality	<i>Born in Ireland</i>		<i>Born abroad; moved to Ireland as an adult</i>	
	11		4	
Living Location	<i>Dublin City</i>	<i>Dublin Suburb</i>	<i>Semi-Rural</i>	<i>Rural</i>
	1	4	6	4
Location of Interview	<i>Parent's Home</i>		<i>Site Based</i>	
	12		3	

Table 7: Parent Characteristics – Number = 15

As has been identified in other studies in children's palliative care, female participation in this research was higher than male (Macdonald, Chilibeck, Affleck, & Cadell, 2010). Three male/female married partners chose to be interviewed together, each in their own home. Two couples lived within the suburbs of the city where the research site is based, and a third couple lived in a rural setting just over an hour from the city. From the cohort of female participants interviewed alone, 5 chose to be interviewed at home, two of whom were based in rural settings within a three-hour drive of the research site. Two men chose to be interviewed alone, one in his home within the surroundings of the city and one travelled to the site hospital for his interview.

At the start of the interview, care was taken to allow for an informal introduction and to thank the participants. Participants frequently offered refreshments and this was accepted, or refreshments were offered by the researcher during on-site visits to help the participant feel more comfortable. Demographic information was gathered and consent forms signed before the recorded interview commenced.

While many parents expressed deep emotions during the interviews, as a researcher, I did not experience any difference in the intensity of the discussion or nature of information that was offered whether the interview was at home or in the research site. When interviews took place in the participant's home, I arrived on time and had a check list to ensure that I had all of the necessary paperwork and equipment. No technical difficulties arose during the data gathering process.

iii. Characteristics of the Staff who Participated in the Research:

Doctors and nurses were selected because of their profession and position held within the hospital and invited to participate through direct email invitation. Health and social care professions ("HSCPs") were nominated through their head of department, and then sent a personal invitation via email which included the Participant Information Leaflet – Staff (Appendix 6). Representatives from physiotherapy, occupational therapy, play therapy and chaplaincy were involved in the HSCP focus group. All staff members who participated had previous experience of providing clinical care to children who were patients of the hospital who had died.

Inclusion Criteria
<ul style="list-style-type: none"> - At least one year post qualifying experience; - At least one year in post at the site hospital; - Worked with families whose child was provided with end of life care and had died.

Table 8: Inclusion Criteria - Staff

A total of 24 staff members took part in focus groups for this research. The purpose of the focus groups was in keeping with the purpose of the research examining the experience of staff providing support to families at EOLC and bereavement. Focus groups were the chosen approach to interviews with staff in order to prompt group discussion and interaction around areas of concern to the participants, (Kitzinger, 1995; Ansay et al., 2004). However, all of these groups were smaller in number than the traditional focus groups, due to the challenges of getting sufficient staff numbers freed up from their frontline duties at the same time. In total, 7 focus groups took place, in various meeting locations around the site. The time and day for the focus group was negotiated with participants via individual email. For some groups, individuals who were invited and agreed to attend did not turn up on the day due to the demands of their clinical work. In another group, one staff member arrived to participate, but reported that he could not stay for the duration of the group and could not turn his bleep off as he was on call. By mutual agreement, we decided that it was inappropriate for him to participate as it would be disruptive to the group. In each group, it was agreed to go ahead with the focus group due to the effort that each individual staff member put into making sure they kept time free for the group. I was also anxious to be respectful to each individual's enthusiasm and commitment to the project.

The chart below sets out the characteristics of the staff participants in this study:

Participants	<i>Medical Consultants</i>	<i>Clinical Nurse Managers</i>	<i>Health and Social Care Professionals</i>	<i>Medical Social Workers</i>	<i>Total Number of staff</i>
Number of staff	3	5	4	12	24
Number of Focus Groups	1	2	1	3	
Age	<i>20-30</i>	<i>31-40</i>	<i>41-50</i>	<i>51-60</i>	
Number of staff	2	9	9	4	
Length of time working in research site	<i>1-5 years</i>	<i>6-10 years</i>	<i>11-15</i>	<i>16-20</i>	<i>21 and over</i>
Number of staff	4	3	3	7	6
Number of years in post	<i>1-5</i>	<i>6-10</i>	<i>11-15</i>	<i>16-20</i>	<i>21 and Over</i>
Number of staff	10	1	6	4	3

Table 9: *Demographics of Staff Focus Group Participants*

Similar to the parents' interviews, a narrative approach to the structure of the focus groups was taken, using the initial generative question to invite each staff member to recount a story of working with a child who had died, followed in the second half of the interview by clarifying questions. Following completion of the demographic data sheets and consent forms, participants were invited to ask any questions of clarification. At this point, the tape was turned on and the generative question asked, followed by one of the group volunteering to talk first. When each participant had discussed the child they had worked with who died, I asked a number of clarification questions, based on the issues raised within the participants' stories.

4.3.3. Using Reflexive Thematic Analysis

Having outlined the rationale for adapting a narrative approach to the research, the chosen method for analyzing the data is what Braun and Clarke (2019) now refer to as "reflexive thematic analysis". This follows a particular approach originated in their seminal 2006 paper in which they set out a clear, defined explanation to thematic analysis as well as setting out a structured framework for its implementation. The decision to adapt this approach to analysis of the data allowed for an exploration of the data within the narrative framework to connect the stories told through place, time and context (Clandinin, 2007).

In later papers, Braun & Clarke (2012, 2014, 2019; Clarke, Braun & Hayfield, 2015) set out more of the rationale behind their approach, providing responses to the criticism that, while their 2006 paper was useful, it made assumptions about the authors' ontological and epistemological beliefs (Braun & Clarke, 2019). As an overarching principle, Clarke et al. (2015) state that thematic analysis is a tool rather than a framework and should be used in conjunction with the researchers' chosen research paradigm, particularly in relation to the questions of the specific methodological approach being used. As already noted, this narrative inquiry was analysed from an inductive, experiential and social constructionist perspective. The development of the codes and themes was driven from the data, not imposed by myself as the researcher.

Braun and Clarke's (2006) six-stage process for analyzing data was followed in this research. Key to their approach is the creation of codes and themes. They suggest that codes should be seen as the "building blocks" of any data analysis, whose descriptors summarize an aspect of the data (Braun & Clarke, 2012). Codes are the first step in interpretation of the data content and can be either semantic, describing an idea or concept, or latent in that they suggest an underlying idea or concept (Clarke, et al., 2015). The second key concept is that of themes. Codes are reviewed by the researcher to look for associations between them to initiate a process of "identifying, analyzing, and interpreting patterns of meaning" or themes (Clarke, et al., 2015, p. 297). To ensure rigor in creating the themes, a two-stage process (see step 4 in Table 10 below) is undertaken in checking the themes against the data underpinning the theme and against the entire data set (Clarke, et al., 2015).

Following confirmation of the selected themes, they are then reviewed to see if one overall concept or shared idea emerges (for an example of this process see Appendix 7). The final step is for the researcher to write up their findings, using samples from the codes and themes into a coherent discussion of findings in relation to the overall research question. Braun & Clarke's (2019) decision to re-name their approach as "reflexive thematic analysis" embodies the rigour or "knowingness" that is essential to this approach and which, I believe, is evident in the analysis within this research. They state:

"By knowingness, we mean evidence – in the writing – of research being treated as a deliberative process, one that involves decisions related not just to design and method, but ontology, epistemology and methodology, and rationales for these, individually and collectively. Knowingness demonstrates engagement with

research as a thought-out adventure, rather than simple ‘recipe following’ activity” (Braun & Clarke, 2019, p. 591).

In the chart below, Braun & Clark’s six phase structure is outlined with the practices undertaken by this researcher at each phase of the analysis:

Phase	Practices Undertaken
1. Familiarization with the data:	<ul style="list-style-type: none"> a. Note taking following interview b. Transcription of the interviews c. Initial Readings of the Transcript d. Note taking following initial readings
2. Generating Initial Codes	<ul style="list-style-type: none"> a. Coding of entire transcript b. Multiple coding of data extracts if appropriate b. Uploading of codes to NVivo as data management instrument
3. Searching for Themes	<ul style="list-style-type: none"> a. Review of the entire data set and all of the codes created b. Search for broad topics or issues c. Creation of Candidate themes, with all of the associated codes listed d. Create a category with miscellaneous codes d. Creation of a mindmap with potential themes
4. Reviewing Themes	<p>Part 1 – within theme</p> <ul style="list-style-type: none"> a. Review of all themes b. Review data and recode for any missing data c. Revision and refinement of all themes to ensure they have sufficient data to support them d. Creation of a mindmap of confirmed themes and their relationship to each other to form a pattern <p>Part 2: Within entire data set</p> <ul style="list-style-type: none"> a. Examine how each theme from Part 1 relates to the other b. Ensure that the mindmap created in Part 1 fits for the entire data set
5. Defining and Naming Themes	<ul style="list-style-type: none"> a. Review themes with a view to looking for a cohesive overall organising concept b. Collate data for each theme c. Write a detailed analysis of each theme d. Describe how the themes fit with the organising concept, supported with extracts from the data

6. Producing the Report	<p>a. Create a report that can describe the organizing concept and themes including their complexities and nuances in a cohesive way that is convincing for the reader</p> <p>b. Ensure that the report includes compelling evidence from the description that convincingly applies the evidence to the research question</p>
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Table 10: Braun & Clark's Six Phases Structure for Thematic Analysis (Adapted from Braun & Clarke 2006, 2012)

In this research, each of these phases was undertaken in the analysis phase in consultation with my academic supervisor.

4.3.4. Use of Data Analysis Software

During the process described above, the data management software package NVivo was used. All of the transcripts were uploaded and coded onto the system in order to facilitate the management of such a large amount of data. This allowed for the easy retrieval of sample extracts under different codes and provided a numeric count on the number of segments of data in each code which facilitated the verification process as themes emerged. However, as Bold (2012) suggests, and was my experience – “[s]oftware packages do not do the analysis; they assist with practicalities of sorting and classifying the data” (p. 130).

4.4. Ethics in Narrative Research

As discussed in the previous section, having a clear ethical framework for any narrative inquiry is critical. In carrying out research such as this, it is critical that the researcher take account of the sensitive nature of research in the field of bereavement and the possible vulnerabilities of possible participants. Arising from concerns about unethical medical experiments in the 1940s, the Nuremburg Code (1949) was developed to provide rudimentary guidance to researchers about participant safety. An ethical approach encompasses the need to address moral, instrumental and pragmatic issues within the research. Ethics is a key consideration for any professional social worker and social work's professional bodies provide frameworks of ethics to guide research (Drisko, 2013a; Reamer, 2013; Shaw & Holland, 2014). In their most recent iteration of their Code of Ethics, National Association of Social Workers (“NASW”) in the US, clearly

define research as one of the applicable areas for this code (NASW, 2016). More locally, CORU, the professional accreditation body for social workers in Ireland, specifically include research within the area of applicability for their Code of Professional Conduct and Ethics for Social Workers (CORU, 2010).

As Carey (2012) suggests, there are rarely clear answers to the ethical (and moral) questions raised by research. Espousing a “do no harm” approach could be questioned ethically, if the researcher does not build safeguards into their research approach to ensure that participants are protected from undue stress or demands placed on them by the research (Shaw & Holland 2014). For example, in this research, parent participants were offered the possibility of undertaking the research interview in their own homes. This option recognised the possibly diminished energy levels of bereaved parents, and also allows them to remain in the comfort and familiarity of their own homes to reduce any level of discomfort they might experience in coming back to the hospital where their child died. Carey (2012) suggests that, at its worst, unethical research could damage and distress participants. The ethical research framework of this study, discussed in Section 4.4.1. of this chapter, outlines possible difficulties that might have arisen during the research process and included steps to address those issues should they arise.

Flick (2009) in his discussion of the need for ethics in research points to Murphy and Dingwall’s (2000) “ethical theory”. This framework can be usefully used as a broad guide to the development of an ethical framework for research. Murphy and Dingwall (2000) hold that ethical research should adhere to the principles of:

- *Non-Maleficence* – in that researchers should avoid harming any participants;
- *Beneficence* – that research that is undertaken with human participants should “produce some positive and identifiable benefit”;
- *Autonomy or Self-Determination* – that any research participant decisions during the course of the research should be respected; and
- *Justice* – that all participants are treated equally.

I believe that the design of this research as set out in the earlier parts of this chapter adhere to all of these basic guidelines suggested by Murphy and Dingwall (2000). For

example, the clear structure for recruitment of participants using the support of a gatekeeper clearly protects the participants and provides support to them should any issues arise during the research process, be that emotional upset or a decision to withdraw as a participant.

Going beyond these broad principles, Bauer et al. (2000) suggest a researcher needs to examine the core structure of the research to find the areas to be considered within an ethical framework. In addition, the researcher can adopt a position of “ethical reflexivity” to support their position of personal moral reflexivity and integrity through the monitoring and active review of everyday ethical issues throughout the research (Mackworth-Young, Schneiders, Wringe, Simwinga, & Bond, 2019). The framework created by Mackworth-Young et al (2019) was used on a regular basis in this study to monitor any ethical issues that arose during the research.

In each section that follows, I will outline the key elements of the ethical research framework of the present study that made this research ethically safe in its execution.

4.4.1. Ethical Issues within the Research

The safety structure provided to participants by the ethical framework created within the research is not a static. It requires revisiting and revising at different points within the research, what Valentine (2007) refers to as the “microethics” of research. For researchers, living ethical questions can arise at any point during the research process from recruitment of participants, to undertaking of interviews, transcription, analysis and presentation of results. The invigilation by the researcher of the steps that they are taking within the research process to ensure the work continues to be ethical is critical. Mackworth-Young et al.’s (2019) framework of “ethical reflexivity” allows for the monitoring of these issues, suggesting the encapsulation of steps to ensure: the continued monitoring of the psychological and emotional benefits to the participant; the negotiation of the researcher/participant relationship; protection of confidentiality; data ownership; and the researcher obligations at the end of the research. Depending on the type of research being undertaken researchers may wish to add other aspects to be monitored, including the impact of the research on the researcher. The issues raised by this concept of “micro-ethics” within the present study are reviewed below.

i. Use of Gatekeepers: The use of a “gatekeeper” was an essential part of the ethical framework set out within the research to protect families from being over-influenced by the researcher to become involved in the study. In the setting where the research is based, each family is provided with a social worker who will support them through EOLC and through the early stages of their bereavement. Some of these social workers volunteered to become a gatekeeper in the recruitment process by being the individual to contact the family and discuss the option of involvement with the research and answer questions about it. Such a level of enthusiasm and commitment comes from a very positive motivation of wanting to improve practice both individually and within the organisation (Devers & Frankel, 2000). However, they also caution that the researcher may need to keep a distance from the gatekeepers at times (Devers & Frankel, 2000 p. 266), particularly if the gatekeepers have concerns about the time needed for the research, or how they or their role might be perceived within the research, especially if there were negative aspects of their role that came up. I found that requesting check-ins with the gatekeepers to see how recruitment was progressing was an essential part of my role as a researcher. The gatekeepers were reassured that their co-operation was voluntary, and that the time demands would be as contained as possible (Singh & Wassenaar, 2016).

During the research, however, it was critical to reflect on the number of times that I as the researcher spoke with gatekeepers to ask for an update on recruitment. I realised early on that the gatekeepers had first-hand knowledge of the family, the current challenges they faced in their bereavement and the possible impact that participation might have on them. The gatekeepers were also very busy individuals who may not be able to take the time for talking with families at the pace that I would have hoped for. In the end, I decided on a friendly, brief reminder to gatekeepers, asking for an update on the recruitment process ensuring that I could keep track of recruitment without putting too much pressure on the gatekeepers.

ii. Selection of Families for Recruitment: In order to protect the families involved and to avoid any role confusion for families, it was agreed that from the outset of the research, no families where I had been their primary support social worker during EOLC and death of their child would be invited to be involved with the research. This resulted in some families who would likely have chosen to be involved in the research not being invited to participate.

iii. Recruitment of Siblings: In the original proposal for this research (including in the Ethical Submissions) permission was granted to include surviving siblings age 5–18 in the research. A question about sibling involvement (if appropriate) was included when gatekeepers spoke to the families about the research. However, due to a combination of a low number of surviving siblings who were over 5, and the hesitancy of parents to expose their surviving children to a research scenario, too few siblings agreed to be involved in the research. Sadly, the decision had to be made to abandon the possibility of their involvement in this research.

4.4.2. Researching with Vulnerable Populations

In undertaking research with parents who are bereaved, it is incumbent on the researcher to address the issues of participant vulnerability. The examination of this issue, of course, brings with it an inherent question about what is meant by “vulnerable” and if it is the same as the term “sensitive population”, another term used within the research. Sieber and Stanley’s (1988) definition of sensitive subjects as areas “... in which there are potential consequences or implications, either directly for the participants in the research or for the class of individual represented by the research” (p. 49). This definition provides a useful introduction to the breath of consideration that needs to be given to this topic. However, if taken from the broadest perspective, it might dissuade any researcher from investigating any topics that might have potential for a negative consequence. Using their definition, therefore *sensitive* could be defined as high risk and act as a discouragement for researchers seeking new knowledge on less well-known topics.

Another approach is to perceive sensitive research as topics that could be threatening in some way to those who participate. Renzetti & Lee (1993) raise a concern about the potential cost to participants of being involved in research. What needs to be remembered is that research has a cost to all involved, at minimum of their time. They go on to present their own definition which is “a sensitive topic is one that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding and/or dissemination of research data.” (Renzetti & Lee, 1993, pg. 5). While this definition develops some of the concepts from Sieber and Stanley’s (1988) earlier work, its use of ambiguous terms such as “potentially” and “problematic” provide scant reassurance for a researcher trying to define whether or not their research would fit into this definition. What is clearer, however, is that the sensitive nature of any particular research cannot

be definitively defined at the outset. While a researcher may approach a topic as sensitive, it may not turn out to be so within the field, and *visa versa*. The key position, according to Renzetti & Lee (1993) is the researcher's awareness of the possibility of the topic being sensitive and to the possibility of harm both to the research participant and, indeed, the researcher herself.

More recent definitions continue to provide the researcher with few clear guidelines and encompass a wide potential for research participants to be considered vulnerable. Alexander, Pillay & Smith (2018) provided a systematic review of published articles that examined the attitudes of participants and researchers to the inclusion of vulnerable populations in research. They conclude from their work that there is no clear evidence that participation in research is harmful to vulnerable populations. They add that the evolving thinking about vulnerability in research suggests that it should be defined "as a complex, multi-dimensional concept continually evolving according to societal values and beliefs" (Alexander et al., 2018, p. 86). Indeed, Alexander and her colleagues argue strongly that we should not be asking if vulnerable populations should be involved in research, rather asking why they are *not* involved, as they often provide a unique perspective on topics that are the subject of research.

While the definitions in relation to vulnerable populations may not be clear, what is certain is that a strong ethical framework for such research is essential (Alexander et al., 2018; Sieber, 1993; Valentine, 2007). An ethical framework that, firstly, does no harm to the participants (and arguably the researcher), is critical. But frameworks that also allow participants benefit from the other key ethical standpoints of autonomy, beneficence and justice are essential parts of the planning that the researcher needs to take into consideration. Asking "why not" include certain groups in research work becomes possible if the researcher ensures that the ethical framework provides protection to the participants. Within this research, a "Participant Welfare Statement" was prepared but was not needed during the research (see Appendix 8).

4.4.3. Code of Ethics

Monitoring relevant Codes of Ethics is an essential part of social work research (Carey, 2012; Drisko 2013a). Other ethical codes required in relation to this study included the ethics of the hospital (research site) and the Code of Ethics of the University where I am a registered PhD student. A number of professional guides such as the International Federation of Social Workers/International Association of Schools of Social Work (2004)

statement, the CORU Code of Professional Conducts and Ethics (2010) and the British Association of Social Worker's Code of Ethics for Social Work (2014) make mention of social workers as researchers. They all include the expectation that social worker in the role of researcher will adhere to the ethical code as set out. The National Association of Social Workers' (US) Code of Ethics in particular holds that researchers should ensure that they do not unnecessarily intrude on participants (Webster, Lewis, & Brown, 2014). While acknowledging that the richness of research may be compromised if researchers avoid broaching difficult topics, it is clear that researchers should put in place mechanisms to avoid any undue burden on participants (Webster et al., 2014).

4.4.4. Values

All researchers need to recognise that values are an integral part of any work undertaken (Bryman, 2012). There is an explicit value base within social work that "permeates through with its critical and reflexive mindset" that influences any social work practitioner (Hardwick & Worsley, 2016, p. 346).

Therefore, in addition to providing a framework for research practice, professional codes of ethics and the chosen research methodology provide the researcher with a framework of values to adopt within their research. As outlined above, few broad social work codes of ethics are specific in their guidance for social workers as researchers. These documents, however, do provide excellent enumeration of social work values, which can be used by social work researchers to support the ethical framework developed in their research. For example, the BASW's statements of "values and ethical principles relating to human rights, social justice and professional integrity" can be most helpful in guiding social work researchers to identify and plan for ethical issues (such as limits of confidentiality, caring for participants etc.) that will arise during the research (BASW, 2014, p. 5). Its statement of value about individual service users promoting "respect for the inherent worth and dignity of all people" is as equally valuable when approaching research as it is in approaching practice (BASW, 2014, p. 8). This statement, for example, reminds the social work researcher that the need to gain information and knowledge within the research process should not result in any disrespect of the worth of the participants. It would equally ensure that the researcher includes all voices in the research, not just those of the majority group within the potential participants for the study. In this research, this meant the inclusion of families whose child died from a wide range of illness, or where the family are from a minority culture.

The process of being explicit about the value base, and reflecting on same, strengthens the ethical position taken by the researcher. It provides, according to Lincoln et al. (2011), trustworthiness and authenticity. The research then becomes what Padgett (2009) describes as a “*trustworthy*” study “carried out ethically and whose findings represent as closely as possible the experience of the participants” (p. 102).

4.4.5. Ethical Approval

In order to ensure that this research proposal was ethically sound, it was reviewed by two Ethics Committees, that of the research site and that of the School of Social Work and Social Policy of the university I am attached to. Approval from an ethics committee allows the researcher to be assured that their research is ethically sound (Flick, 2009).

Hospital Ethics Committee: Within the children’s hospital, all researchers must complete a detailed written application for Ethical Approval for their research which includes details of the background to their study, research questions and aims, and summary of methodology. The application asked for details of how the researcher proposes to inform potential participants of the research, how informed consent will be sought and how support is to be provided to any participant should it be needed. Ethical approval was granted to this researcher in August 2018.

University Ethics Committee: This committee, based within the School of Social Work and Social Policy, again requires that the student complete a detailed application form outlining the details of their proposed research. Ethical approval was sought and granted to this researcher in September 2018.

The rigor imposed by working through these two applications and approval processes provided strength to the ethical framework set out within this research proposal.

4.4.6. Issue of Researcher “visibility and accountability”:

Lainson (2020) holds that in a narrative inquiry, the researcher needs to be visible and accountable in acknowledging the influences, both personal and professional, on their role as a researcher because

“... narratively informed research cannot subscribe to the positivist notion of an objective, impartial researcher reporting expertly on essential truths about problems, or even naively acting as a conduit for people’s stories” (Lainson, 2020, p. 73)

The process of examining how the researcher might influence the research process or outcome through their personal and professional beliefs is now a critical element of qualitative research (Finlay, 2002). It requires the researcher to examine their own values, beliefs and experience of the subject under research (Blythe, Wükes, Jackson, Halcomb, 2013). Reflexivity allows the researcher to acknowledge the “muddiness” of the researcher’s influence (Finlay, 2002) and address the ethical difficulties and challenges that are a key part of any research (Flick, 2009).

In reflecting on my own personal and professional history, I believe that it is important to acknowledge a number of strong influences. From my personal life, formative experiences of personal bereavement, both as a child and an adult were kept in mind during this study, as well as the highly emotional experience of medical complications while pregnant and during the birth of both of my children. During these latter experiences in particular, I came to understand how close intimate relationships can be built with key health care staff on whom you depend for your own life and the life of your child. These bonds, forged of utter necessity, became, for me, a lifeline that dragged me through those fearful days, allowing me to form a deep personal understanding of a parent’s fear, of the desperation for reassurance, of the need for clear and unambiguous communication, of the dependency on expert knowledge. I often remember those experiences when I go to meet parents whose child’s life is threatened by ill health and it brings to my practice a strong motivation to be part of the team who hold and nurture these families during these medical crises, whatever the outcome. These personal experiences are a strong motivator for undertaking this research.

My current professional practice is strongly influenced by the families I have met and worked with for the past 12 years in a children’s hospital, encountering hundreds of families whose children have faced serious illness. Their resilience and strength are inspirational for the staff who care for them, while their struggles are so painful to witness. Standing alongside them in their journey, challenging as though it may be, is a privilege. Additionally, my professional practice in EOLC and bereavement stands on the memory of those young women and men who died during my years of working with those affected by HIV and AIDS in the late 1980s and 1990s. So many expressed a wish, as they faced death, that the story of their lives and their struggle would continue to have meaning after

they were gone. Weaving the lessons learned while working with them, of “being with” when there is no hope of a medical cure, of preparation and planning for a death, of the importance of respect for the body after death, of the impact of grief that cannot be spoken, remains part of my work today and enriches my ability to be present for those families facing death. In this small way, their lives and struggles are not forgotten.

So I approached this research as a woman, a bereaved person, a mother, a social worker, a reflective practitioner, a family therapist, a student, and a lobbyist in the area of childhood bereavement. All of these experiences, personal and professional, together with my professional and academic training, make up the whole of who I am now as a professional researcher.

One of the ways that this experience might show its influence is in my position as a practitioner researcher. As a social work practitioner and manager in the field of children’s EOLC and bereavement, I am undertaking research and generating knowledge directly from practice (Salisbury Forum Group, 2008). Using this approach provides benefits in that I am familiar with the setting and the nature of the work which can develop a level of trust with participants (Arber, 2006). However, it requires the researcher to remain mindful of the impact of her own bias and include approaches in the research methods to acknowledge and address that bias (Lietz & Zayad, 2010). To do this, the researcher “brackets off” their presuppositions during the period of the research to address concerns about the “insider status” (Denscombe, 2014, p. 99). This bracketing off was based on the following practices in this research by this researcher:

- Memo writing throughout the research (Tweed & Charmaz, 2012)
- Consultation with supervisor
- Consultation with an Expert Advisory Panel to assist in the research consisting of academic experts, experienced professionals and “experience consultants” who are parents the researcher has worked with who are at a later point in their bereavement.

As Shaw and Lunt (2012) state, the practitioner’s experience is “outside, or at least at the margins, of research and practice – an uncomfortable but creative marginalization marked by an identity that is neither research nor practice” (p. 109).

While more usually defined as having personal experience of the phenomenon being studied (Blyth et al., 2013), if a broader definition of “insider” knowledge is used (Foster, 2009), I need to ensure that the knowledge of this field I have gained through professional practice in the field is acknowledged. The challenges to be recognised in relation to insider status include: “assumed understanding, ensuring analytic objectivity, dealing with emotions and participants' expectations” (Blythe et al., 2013, p. 8). My professional experience and connection with the organisation where the research took place means that I was researching with individuals who are colleagues, requiring me to take a temporary “outsider” position, adopting an attitude of “doubt” towards procedures or perspectives that are taken for granted (Flick, 2009, p. 111). According to Shaw and Holland (2014) taking a “monopolistic” approach, that only insiders can gain knowledge is unhelpful. Rather, they espouse an approach that recognizes a more “muted” version of this position. “Th[is] ... form of doctrine claims that Insiders (*and* Outsiders) have *privileged* rather than *monopolistic* claims to knowledge” (Shaw & Holland, 2014, p. 38). This allows the researcher to take account of both the Insider and Outsider knowledges in the process of creating new knowledge within the research, which White (2001) describes as an “insider out” position.

Using the methods outlined above, I ensured that the expectations, knowledges and assumptions that I may hold about the research or its findings were acknowledged within the research process. As Foster (2009) so passionately exclaims: “We can no longer assume that any research is without bias.” (p. 18).

4.4.7. Researcher Self-Care

As a social worker of many years standing, in the area of EOLC, many benefits accrue from that experience that can apply within this research. An ability to understand the sensitivities of the topic being researched, a confidence in interacting with bereaved families, a familiarity with the emotional journey of bereaved families at EOLC and in their bereavement, facilitated the process of data gathering. My familiarity with the research setting allowed for ease of access, while the process of gaining ethical approval from the organisation ensuring that no undue influence was gained because of that insider knowledge.

As a seasoned professional, well used to undertaking office and home visits, researcher safety both physically and emotionally is built into the design of this research. For example, when I was undertaking an interview alone in an area of the hospital site that is away from others, or indeed undertaking a home visit, the safety protocol usually in

place for my professional practice was adhered to. In addition to these safety measures, a mobile phone was carried at all times when undertaking interviews, and the principle of “researcher safety first” was in place but was not required during the fieldwork phase.

Recognising that interviews of this nature could be highly emotional, I also had available to me the facility to debrief with an experienced colleague who was based on site if needed. However, I recognised that capturing the emotional impact of such interviews can be a source of rich information during a research undertaking of this nature and the memo writing procedure described earlier was used to capture this information for later reflection during the analysis of any individual interview. It further facilitated the processing of the emotional content of this work. For this purpose, Gilgun’s (2013) perspective on the emotional impact on the research was kept in mind.

“The knowledge we gain ... is not information that simply passes through the central processors of our brain. It also arises from our hearts and often our deeply held emotions. Understandings gained through an engagement of heart and mind have an immediacy that potentially connects to the hearts and minds of audiences” (p. 121).

No issues of physical safety occurred for me during the research process. However, consistent reflexive practices and self-care were required throughout the period of fieldwork in order to manage the emotional impact of the interviews, particularly with parents. The creation of detailed field notes served as a “debriefing” after each interview. Unexpectedly, this emotional impact of transcription took a high emotional toll on me due to the necessity to repeated listening to the audiotapes in order to ensure that it was accurately represented in the transcript. In discussion with my fellow students in college, we identified this issue as a common interest among us and as a result I prepared and lead a seminar for PhD student peers on the topic of the “emotional labour” of the researcher (Dickson-Swift, et al., 2009). In addition, regular meetings with my PhD supervisor allowed me to discuss and reflect on this process. Within the process I learned that, while the skills learned during a lengthy period of clinical practice in this field were helpful, the experience of being a researcher blurred the professional boundaries, particularly as I was so openly invited into participants’ homes where they shared their stories about their children even before the interview began. As a researcher, I came to understand that I was now in the very different position of asking something of people I could, in other circumstances, have been providing a professional

service to. However, as I began to hear the responses from parents as I asked them at the end of each interview about what the experience of doing the interview had been like for them, their positive feedback about the importance of participation as an act of remembrance of their child, and in being appreciative for the care both they and their child had received, I was reassured and strengthened in managing the emotional impact of the research.

4.4.8. Confidentiality

From an ethical perspective, any researcher needs to be clear about the confidentiality of any materials gathered from participants during the course of the research (Webster, et al., 2014). According to Reamer (2013), the use of narrative methodology encourages openness and transparency with participants, allowing the researcher to be clear to participants about the nature of confidentiality, as well as any situation that may arise that would not allow the researcher to maintain that confidentiality in an unlimited way. In a study of this nature, the area most likely to cause concern for the researcher is the possibility of a high level of emotional distress in the participants. The research included a very clear limitations clause within the participants information leaflets (Appendix 5 and 6) in relation to the emotional safety of the participants. There was agreement that, if the researcher is concerned about the parent participant's emotional distress, then the researcher would reserve the right to share this with the social worker who is working with the family. This permission was included in the consent to be signed by the participant so that they have knowingly agreed to the researcher sharing these concerns with the medical social worker working with the family, in order to pursue appropriate supports for the individual participant. For staff members, information about sources of support within the health care system were provided to ensure that they could seek support after the focus group if needed.

4.4.5. Conclusion

This chapter has provided an overview of the methodology and methods adapted for this narrative inquiry. Details of the research paradigm adopted, in addition to an overview of the tenants of narrative inquiry are included. The methods for undertaking the research were described in detail including an outline of the research question, the recruitment procedures and the structure of the interviews and focus groups undertaken. A detailed section on the ethical approach adopted for this study concluded this Chapter.

CHAPTER 5: PARENTS' EXPERIENCIES OF THEIR CHILD'S END OF LIFE CARE: ENTERING & EMERGING FROM LIMINALITY

In the previous chapter, the methodological approach to the study was set out and the approach to the recruitment and interviewing of parents and staff was explained. This chapter presents an exploration of the findings from the analysis of the interviews with parent participants using the framework of liminality as proposed through the work of Arnold Van Gennep (1903/1960) and, later, Victor Turner (1967, 1969) which was used as a theoretical lens in data analysis. Within the analysis of the parent interviews, three themes were identified, describing the parent's experience in children's EOLC. These themes are: 1) Entering the liminal space of End of Life Care; 2) "Being" in Transition; and 3) Emerging from Liminality. Each theme will be discussed in detail. However, prior to that discussion, an introduction to the parents and their children and a discussion of the approach to analysis of the parent data is presented.

5.1. Introducing the Parents and their Children

Before discussing the findings from interviews with parents, it is important to be reminded of some of the background of the parents who were interviewed and the children who died and remain such an important part of their lives.

Parents: As discussed in the previous chapter, 15 parents were interviewed for the purposes of this research. They included 10 mothers and 5 fathers, with three sets of couples requesting to be interviewed together. Their ages ranged from 31-54. 12 parents were married, two were single parents and one parent had separated from their spouse since the time their child died. 14 parents were birth parents of the child who died and one was a long term foster parent. Participants occupied a range of professions with some parents not currently working at the time of interview. Four parents interviewed were not born in Ireland, one from Europe, one from North America, one from Eastern Europe and one from Asia. Two parents did not have English as their first language but were happy to be interviewed in English. Some parents lived close to the research site, within the city suburbs, and in the surrounding counties, and some parents live at a considerable distance from the site hospital (200 to 300 kilometres), their children having been moved to the site hospital as their local hospital did not have PICU facilities.

While having diverse backgrounds, what bound these parents together was the love and pride they had in their children, and their deep sorrow at their death. While not asked directly to discuss or describe their child's character or the quality of their relationship, parents offered insights into the deep bond each held with their child:

"I am very proud of her, yes from the beginning (Par014)

"he's the strongest boy ever, [...] he was tall and big" (Par011)

"I love her, like [child] she was my life, she was my first girl, ye know, [...] so I flooded, overflowed her with love, and she [child] was mine and she got flooded with love." (Par012)

This bond was particularly evident within the preparatory stage when interviews took place within the child's home. For some parents, this preliminary stage was an opportunity to introduce me (as researcher) to their child through connection with their "transitional objects of grief" (Goldstein et al., 2020) or "memory anchors" (Meert et al., 2009). This concept of having objects that brought connection to their loved one was clearly evident, particularly when the interview took place in the participant's home. These "memory anchors" in the form of tangible objects are treasured by parents as they provide a physical connection with the child and ensure that their connection to the child will not fade (Meert, Thurston, & Briller, 2005, Meert et al., 2009). For one parent, it was showing me the only family photo of them all together, taken by the hospital photographer while they were in the hospital. Another parent remarked:

"And I found it easier in the house, cause we didn't know how that would be and like even you coming in and going "oh look at the pictures" or look at this and you're like oh yea that was this and this" (Par003).

For her, my remarking on the photographs on the sitting room wall of her child allowed her to openly talk about her child who had died, resulting in her being more comfortable within the interview situation. Through these processes, the participant and interviewer had an opportunity to talk about the child, their personality, and their history, building a relationship between the interviewer and interviewee in remembering the child, a key aspect of the interview process (Kvale & Brinkman, 2009).

Children: The 12 children introduced by their parents ranged in age from under one to age 16 and included six boys and six girls. Seven of these children experienced life limiting medical conditions, two experienced sudden on-set illness and three died as the result of a trauma. They were also children who attended playschool, were an integral part of their school community, loved their pets, played Gaelic football, and loved “messin” with their friends. They all brought joy to their families, even throughout their illnesses, as parents described experiences of “having a lovely time” even as their child was dying.

This mother described some of the time spent with her son after he was discharged home to die:

“I wanted him to try to listen to all kinds of music, so like we just all, like I never stopped his cousins visiting the house, so like we always had cousins playing around just wanted him to hear those sounds, and the smells, like I’d bring him out into the garden with me like when and like just have him out in the garden” (Par005)

For this dad, life with his child with a life limiting condition wasn’t just about illness:

“but then there’s always when she’s in your arms and you’re watching telly, there was lots of those beautiful moments, [...] there was an element of, a very simplistic, but a, I think she was, there was loving joy to where she was” (Par015)

For all parents involved in the study, facing the death of their child placed them into a world that they have never experienced regardless of whether or not their child had previously been ill. So, while for some, there would appear to have been time to prepare, most of the parents in this study describe the death of their child as sudden.

While this chapter will set out what appear to be neat themes, with a clear structure, it must also be remembered that these parents’ experiences are set within the context of years of caring for a child with a life limiting condition, or the challenges of having a child who becomes acutely ill. Despite the trauma and challenges they experienced, each family’s story is surrounded by unique narratives of joy and loving, pain and sadness and I have endeavoured to be respectful and true to those experiences while recounting them in this chapter.

5.2. Analysis of Themes

As described in Chapter 4, the analysis of the findings was approached using Reflexive Thematic Analysis, which Braun & Clarke (2019) see a tool to enable the researcher to develop codes and themes that are inductively gathered from the data in order to provide a deeper explanation of the experience being studied. Braun & Clarke's (2006) six step process was followed, beginning with transcription of all data. Multiple readings of the text, with the creation of research notes after each reading, ensured detailed familiarisation with the data. The raw data was then coded, using multiple coding if appropriate and uploaded to NVivo data management system. The codes were then searched to create candidate themes. This process was assisted by the creation of mind-maps to examine potential groupings of codes. All of the themes were then reviewed in discussion with my supervisor, missing data was coded and then all of the themes were examined in relation to each other. Finally, the themes were named in keeping with the overall theme of "Liminality" (Van Gennep, 1903/1960; Turner, 1967; Turner, 1969) which emerged from the data.

The example below sets out the development of the coding process, firstly into candidate themes and then developed into full themes. This example of a parent explaining the process of coming to understand that their child's medical outcome was not certain and the emotional process that was attached to that for them, provided an example of one of the processes for parents as they transition to be parents of a dying child within the liminal space of EOLC.

Data Source	Transcript Extract	Open Coding	Candidate Theme	Theme Review	Defining and Naming Themes
Parent Interview	“We’re gonna do This next but this might happen” “we’re gonna do this next but this might happen, you need to be prepared for the worst at every time”. And we were desperately upset ...” (Par013)	Medical Uncertainty	<i>Facing Medical Uncertainty</i>	Recognising the unknown future for their child	“Being” in Transition

Table 11: Example of the Coding and Theme Development Process - Parents

Through this process of coding and building themes, the exploration of parents’ experience during the death of their child was seen as a transition, highlighting their entry into an experience of liminality (Theme 1), their process of transitioning within the liminal space of the hospital (Theme 2) and the commencement of their integration of their bereavement as they begin to emerge from this liminal experience (Theme 3).

The three major themes that arose were:

- 1) *Entering the Liminal Space of End of Life Care*
- 2) *“Being” in Transition*
- 3) *Emerging from Liminality*

Each theme will be explored in detail, using the concepts developed by Van Gennep (1903/1980), Victor Turner (1967, 1969) and others who have developed these ideas further, particularly in the area of palliative and EOLC.

5.2.1. Theme 1: Entering the Liminal Space of End of Life Care

Within the interviews, parents spoke extensively about what they experienced while their child was dying and the complex emotions and experiences they underwent during that time. For parents, the world, as they had known it, with the knowledge and markers that they had built up within that world, was now uncertain and filled with challenges (Davies et al., 2008; De Graves and Arandas, 2008; Jordan et al., 2015). This phase of separation highlights the “physical or the symbolic detachment of an individual from an earlier fixed sociocultural structure” (Carter, 2016, p. 297). For these parents, that “fixed sociocultural structure” was the expectation that their family life would continue as in the past, by them caring for a child with a life-limiting illness or by being parents who could protect their child from a life-threatening illness or traumatic accident. This process of entering the liminal space is reflected in the two subthemes: separating from the known world; and, beginnings of a transition.

i. Separating from the Known World: Parents identified a number of subthemes that highlighted the transitional characteristics of their experience whereby parents needed to separate and move away from their experience of the world, as they knew it and begin to recognise the change that was happening in their lives.

Being Torn Between Hospital and Home: Parents describe this process commencing with the new necessity to find a way to manage the demands of life at home while being present with their child in the hospital. This experience for parents in this study would reflect Mehta et al.’s (2009) findings that EOLC for a child disrupts the whole family putting it out of its normal routine and requiring everyone to make adjustments, while at the same time trying to maintain some family routines (Brody & Simmons, 2007). In this study, one mother reported that this meant leaving behind the normal everyday routine of life at home, such as daily family dinner.

“my husband came home to make the dinner for us [...] And she got worse again so I had to ring him “leave the dinner there”.” (Par010)

For another parent, it meant dealing with a sense of being “torn” between caring for their sick child in the hospital and their well child at home.

“I felt so torn between leaving [sick child] but [sibling] was only like he was only 20 months so I had to be there for him as well, he was only a baby like, and the only way I could cope was getting [grandmother], and she’s like minded him, but like to be there to put him to bed like.” (Par005)

Indeed, feeling torn between hospital and home eventually strongly influenced their decision to move home while their child died, allowing them to be a family in the same place, saving them from the “toing and froing” they were doing from the hospital. For this father, it was trying to manage the demands of paid employment and weighing up the balance of having an income for the family and spending time with their child, knowing the time was limited:

“I stayed off work for a while and [...] and I went back to work for a few weeks [...] I wish I hadn’t now but I did and I wouldn’t have had any pay afterwards had I not but I probably should have stayed off.” (Par004)

Managing the Distress: Parents identified the high emotional impact for them of living in the uncertain world where their child was unwell, reflecting findings within the extant literature (Bjork et al., 2016; Contro & Scofield, 2012; Melvin & Lukeman, 2000; Monterosso et al., 2007). One parent described it as “like you’re trying to keep all the walls from caving in”. For some parents, the source of the distress was the suddenness and starkness of a child’s deterioration, and the high emotion attached, for example, to a witnessed resuscitation.

“I would always stay with [child] but I just felt I needed to get out o’ here but I didn’t, I just stood back cause there was so many people working on him, without me even realising it they had him whipped out of his wheelchair, they cut his cloths down, I didn’t even see that happen like, so quick ... cause they were trying to get, [sigh], ventilation, they were trying to get bloods, they were doing everything, d’ye know. So I felt quite removed and I felt like I needed to leave the room but I didn’t, I stood there ...” (Par011)

For others, it was the overwhelming nature of the emotions that arose, and the help they needed to manage these emotions. This high level of distress was compounded by a sense of exhaustion and a need for reassurance as the next participant explains:

“So you need constant updates and ye just, ye need reassurance because you’re in a breakdown, you’re having a breakdown then, in every shape and form, you just need reassurance.” (Par012)

The emotional turmoil of this period is also clearly identified with parents identifying distress, exhaustion and lack of preparedness as some of the new emotions that they needed to get used to, reflecting Steele’s (2005) concept of the “emotional work” attached to children’s EOLC. This parent recognised the complexity and confusion he experienced and recounts how he was taken aside by a nurse to have a conversation about his preparedness for his child’s impending death:

“I remember she took me outside and she’s like “are you sure you know what’s going on?” essentially [laughs] and it like “yea acutely aware” like [...] like it’s like, “he’s probably going to go this weekend”, and he didn’t [laughs] [...] I think she just thought I was like completely disengaged from it like, on some level I suppose you are in denial, and there’s a little bit of madness or something creeps in, ye know.” (Par004)

Developing an Understanding of the Child’s Illness: Parents spoke about how they began the journey of managing their experience through developing an understanding of their child’s illness, reflecting Cacciatore et al.’s (2019) findings emphasising the importance of these interactions and their long term influence on bereaved parents. In addition, parent spoke about finding ways to cope through building both their coping capacity and strategies, which mirrors McCubbin et. al.’s (2002) findings that, with the right supports in place, families can find a way to cope with even this most devastating experience of their child’s ill-health. Parents also acknowledged that the trust they were able to build with staff meant that they could manage through this time:

“We never questioned his care and we trusted all the staff, [continues crying] ye know implicitly we trusted them all so we hadn’t been left with questions, we had no questions at all about his care during that period.” (Par013)

Part of their developing understanding was talking with or meeting the medical team involved in their child’s care. For this parent who did not have English as their first language, talking with the doctors, and being informed by them about the deterioration in her daughter’s health, was critical in her understanding of the steps that were taken in

the medical care of her child. She recognised the doctors in their role as experts who would guide her to an understanding that there was no more the medical team could do for her child:

“They had to stop the seizures, the doctor told me all this the night before, that if the seizures are not going to stop, they have to induce her in coma, and they keep her in coma for a few days, for two days exactly, two or three days, and then ... they eh, they take out like, the gas for the coma then to see if she wakes up. [...] from that night the doctors said the one in the ICU, he said ... she, she turns very bad on the brain, the brain is getting loads bigger [...] And he can't do anything.” (Par014)

At times, however, parents acted as their own guides, relying on previous self-knowledge to build their coping capacity. Some parents found taking a break away from the caring situation provided space for their intense emotions. As the next quote illuminates, this involved being together as a couple, away from staff, as they share bad news and begin to realise how seriously unwell their child was:

“I think it gave us an opportunity to fall apart while they [staff] weren't there [...] Like the moment we had together outside, [...] having that time just me and [other parent] to say to me look [...] Look this isn't ... not ok.” (Par007)

Within a liminal framework, these themes represent what Van Gennep (1903/1960) referred to as a “pre-liminal” environment. Parents are entering a world that is unknown, without the foundations of the world that was previously known and with no knowledge of the world that is to come. It is “a psychosocial space, a mix of forces, tensions, missing objects, and experiences” (Kelly 2008, p. 336) referred to by Turner (1967) as being in places and experiences that are “betwixt and between”.

ii. Beginnings of a Transition: Within the research, parents discussed their experience of being new to this liminal world which demands new ways of being. In this first sub-theme, parents described their experience of being in transition by outlining some of their needs as they entered this liminal world of EOLC.

Parent's Need for Information: Parents spoke of their need for information about their child, provided clearly and in a regular manner, as reflected in the studies carried

out by Monterosso et al. (2009). Indeed, good communication has been emphasised within existing literature to support a good relationship between parents and health care providers in children's EOLC (Coad, Patel, & Murray, 2014; Suttle, Jenkins, & Tamburro, 2017). As one parent highlighted, this clear information was particularly critical when her child began to develop new symptoms that she had not seen before and was unclear what they meant.

“And then she was starting having seizures [...] But none of the family or myself we didn't know it was seizures cause we, [...] we weren't like... I hadn't seen before [...] how it looks [...] and what they do [...] cause before even the doctor would, cause before she was ok that way they didn't explain us.” (Par010)

For another mother, the confusion she experienced while her child was being medically assessed became overwhelming, mirroring Marsac et al.'s (2018) concerns about the complexities that can exist during communication in children's EOLC. The following quote describes how this mother felt a need to physically remove herself from the environment, while at the same time pretend that she was alright. She explained:

“but I remember it was just a stream of people one after the other like we were meeting and I always remember I went like “I'm just going out for a second!”, like I was trying to pretend I was grand, and like my head, it felt like my head was going to explode and I remember sitting on the steps outside going, like going and my dad was there going “I think you need to go [home]” and it's like “no I need to find out what's going on.” (Par005)

For another parent whose child was rushed by ambulance to the site hospital following a tragic accident, this clarity of information became critically important, but was not provided, adding to his distress as he entered this liminal space.

“When I arrived, I wasn't like met by a representative like, where, let me see, [...] like I arrived after [wife] and em there was a little bit of a wait and a hustle and a bustle say me dad was there and the Gardai [police] was there at the time and stuff like that, and say em ... it would have been good if there was a representative from the hospital that knew the ins and outs sort of standing for any like urgent questions that needed to be answered straight away like.” (Par012)

Worrying about the Child Suffering: Some parents worried about their child suffering. This finding would reflect the concerns raised by Harris (2004) in his review of the history of CPC for children with cancer, that parents are in a better position than caregivers to assess a child's suffering. For a number of parents, worrying that their child would suffer, either physically or psychologically was one of the key elements of the experience of this phase of their child's illness and added to their sense of distress. Their sense of being "stuck" and not knowing how to fix the situation reinforced their sense of being a novice in this situation. For this father, looking at his daughter during a time when the PICU staff were using a high level of technology to try to help her to breath, brought with it a concern that this resulted in her physically suffering, as he explained in this next quote:

"And em [tuts] this mask had to go back on [child] anyway [starts to cry] [silence] and eh [deep inhalation of breath while crying deeply] [...] [silence] It was over her whole face, and [crying] [silence] I remember looking out and she could never communicate with us [whispering] but I thought she felt really scared [quietly while crying] [crying deeply] [...] and it was all steamed up and there was alarms going off [crying] I think it was stressing her out [crying]." (Par015)

For another parent, her concern about her son's psychological processes during a particularly difficult time in his care, brought concern for her that, in order for their child to manage, he had gone into "shut down" in order to cope with the experience of PICU.

"He wasn't responding and em which was very worrying for all of us, but I also used to say to the nurses, I was petrified for him because I knew that he was so nervous in hospital, so nervous in hospital and here he is in this place, with all these machines. [...] So we were conscious that he was probably in shut down, because he was so terrified, so terrified of being in there." (Par013)

Quality of Life: Parents in this research expressed concern about their child's quality of life as they began to recognise that their child could die, reflecting Lotz et al.'s (2017) findings that quality of life is a priority issue for parents in children's EOLC. In the extract below, this parent highlighted how her priorities changed as she witnessed the physical deterioration of her child, recognising what she believed were the limits to her son having a quality of living. The sequence below highlights the new values that this mother takes on as she begins to assimilate that her child will not survive:

“They always mentioned em “quality of life” for [child] it was a constant “quality of life” “quality of life” like which I hated, I hated the “quality of life” thing ye know like. I could see it towards the end with [child] because of all of his seizure activity and like he lost so much, he used to be able to bum shuffle around and then he just ended up in a wheelchair unable to move, he barely moved his limbs at all em ... so ... I could obviously see what they meant by “quality of life” but they were saying it kind of like way too early d’ye know, I could see it, I knew it was time, [...] there was no putting him through no more ... to come back to be probably very sick again [...] So ... his body had had enough anyway ye know.”
(Par011)

For this parent, the clear information she was provided with by the medical staff allowed her to recognise that she could reference her own belief system to provide a clear boundary around quality of life, recognising for herself that, while she wanted her daughter to live, she did not believe that it would be acceptable for her daughter if she remained in the hospital for the rest of her life. She explained:

“And even to have some problems with like what can happening after seizing so much [deep breath] I was thinking, I’m going to help her and she’s going to get well soon, like even for the mental health like, everything, if she can lose something after the seizures. [...] but just home, not in the hospital [...] Because, ... its not a life for who was well and then to live their life in the hospital, that’s not fair [...] That’s ... like [deep breath] I dunno what to say ... [exhalation] so badly, no, no, it’s not life for anyone, not even for child, not even for parent, not even for other child.” (Par014)

The complexity of this issue however, is highlighted by another father, whose belief system provided a different framework for him, one that suggested that his daughter should be kept alive at any cost, because of the quality that she brought to their lives as a family – “she showed ye how to live, ye know, the meaning of life” (Par015).

In this section, I have highlighted experiences that parents have spoken about that can be understood through the lens of “the transitional-being”, separating from the world as it was before this life event. The parents’ experiences have been examined to show how they separate from their home life and the life when their child was well or well enough to be cared for at home. For Van Genep (1903/1960), an individual entering a liminal

experience became a “neophyte” or novice. Tracing its classical Greek origins, the word “neophyte” can be translated to mean “newly planted”, with its prefix “neo” meaning “new” combined with the verb “phyein” meaning to “bring forth” or “produce” (Merriman-Webster Dictionary). Perhaps, Turner’s description of this identity as “transitional-being” is more appropriate although he does warn that this novice status brings with it “ambiguity and paradox, a confusion of all the customary categories” (Turner, 1967, p. 97). This section of the discussion showed how parents separated from the world they had known, becoming a transitional-being within the world of EOLC where their child is dying.

5.2.2. Theme 2: “Being” in Transition

This theme examines parent’s experience of living in liminality within the bounded and structured space of the hospital. It highlights how parents experience being in the liminal world and the changes that they need to make in their everyday beliefs and values in order to understand the space that they find themselves in. Central to this middle phase of liminality are the concepts of space and time.

Hospital as a Liminal Space: Within liminality, the concept of space is central. Spatiality is interpreted to mean not just a physical space in which the transitional-being undertakes this experience, but a psychological space that the novice occupies during this time (Braude, 2012; Thomassen, 2012). In this study, the hospital is the key space where parents experience this liminality. They identified the various places within the hospital that held particular meaning, especially the PICU, the ward, and the ED. Parents’ experiences of these spaces often reflected the confusion and contradictions that characterise the liminal process. Parents reported their hope for their child when they were moved from a local hospital to the research site hospital, in that it represented the most advanced medical expertise available. They also reported thinking of it as the place where they first saw their child dead and the place where they started their journey home with their dead child. Particular places within the hospital held different meanings for parents. For example, one parent reported their sense that the PICU represented the marking of a serious deterioration in their child’s health, while another believed it represented the greatest possibility that their child would be saved. Parents also recognised the ED as a place of sanctuary and help, as well as a place of trauma.

The patient experience in a hospital, and even the physical building itself can be perceived as a liminal space, as patients and their families attend for life changing or life-saving procedures (Jordan et al., 2015). Children as patients, and their parents who accompany them on a fulltime basis, remove themselves from everyday life and live in a highly charged environment where their previously known world changes (McKechnie et al., 2010) with transitions for both child and parent occurring in parallel. For many, the experience of being in hospital brings a new identity, as their future is redefined by the impact of their illness (Long et al., 2008). In addition, Turner (1967) suggested that liminal spaces are critical to the transitions inherent in rites of passage. They are the places where the critical elements of liminality including “communication, connection, encounter and renewal” take place, providing safe and protected space for this experience (McKechnie et al., 2010). During the middle phase or “limen”, protected space is particularly important for the neophyte as they experience being “‘no longer’ and simultaneously ‘not yet’” (Wels et al., 2011, p. 1). Parents in the present study identified the strong emotions they attached to the physical space of the hospital as a part of their experience of liminality or transition:

“[they] brought him back to one of the, ... the room I hate, its one of the cubicles he'd been in it before and I hate it” (Par011);

or the emotion attached to the hospital site:

“it's like this is here I know I got the news, so like I kinda died here if ye know I mean.” (Par012).

Temporality as Experienced in the Hospital: The second key element of this period of liminality is the concept of temporality or the meaning of time. The building of the hospital can provide a sheltered space with protected time away from some of the everyday tasks of family life, such as food preparation or other family responsibilities (Dahlborg Lyckhage & Lindahl, 2013). In addition, the building served to provide temporal spaces for families, spaces where they could be with their child and became a shelter away from the responsibilities of their former life.

In relation to the chronology of time (Ricoeur, 1984), many parents remembered the day or the date of key events in their child's end of life journey. As this father described his daughter's deteriorating health, he reported:

“I remember it was a Friday, em, [silence] and they took the mask off [...] Saturday, Sunday was really bad”. (Par015)

For others, however, the uncertainty of EOLC meant that time could not be understood through the lens of chronology, denying them the structure that chronological time normally brings:

“Em again obviously they couldn’t give us time, whether it was a week, or a month, whatever and I think there was a mention at some stage about two weeks but that wasn’t so.” (Par004).

In relation to the phenomenon of time (Ricoeur, 1984), one father described the complex reworking of his previous beliefs and understanding of the world that his son should be able to be kept alive after a very serious accident, while at the same time facing key “decisions” about his care within the hospital which would result in the ceasing of any active treatment and his subsequent death:

“I suppose you have to make those decisions in such a short space of time, I found it very difficult because, deep down inside while while while you’re told there’s no hope you are still in the zone where you’re kind of, is there something? Could he be the one in one thousand or one in one million? You’re still in that zone really.” (Par001)

For parents in this research, they also emphasised the psychological aspect of spatiality and temporality, identifying the demands of managing their child’s care within this liminal environment. Having described their experience of entering liminality when their child became ill in the previous section, this theme highlights their experience of the hospital as a liminal space emphasising the particular emotional and psychosocial challenges that parents experience during this time. The particular areas highlighted by parents are: recognising the unknown future of their children; creating trusting staff/parents relationships; and wayfinding within the liminal space.

i. *Recognising the Unknown Future of their Child:* The first subtheme that parents identified was recognising the unknown future of their child. In this subtheme, parents spoke about the process they experienced during the time that their

child's future was evolving. For all of the parents in the study, they would see the starting point of this process as either their recognition that death was a possibility for their child, or when this possibility was introduced by the staff caring them.

Facing Medical Uncertainty: The first of a number of key experiences that parents described was how they faced and dealt with the absence of medical certainties in relation to their child's care. Indeed, De Graves and Arandas (2008) found in their study that medical uncertainty has a profound effect on families during their child's illness. As parents in this study struggled to understand the new landscape that they found themselves in, they described the "delicate and volatile tipping and turning points" that existed as they recognised and developed an understanding of their child's situation (Stenner et al., 2017, p. 142). Parents described struggling to recognise the serious deterioration in their child's health, the uncertainty of their child's care going forward and whether or not the time was appropriate to cease active treatment. In addition, parents described struggling with not knowing the timeframe for their child's death. McKechnie et al. (2010) describe this as the process of "crossing" into the psychological recognition that death is near. For some parents, crossing was difficult and challenging, but allowed them to be present during their child's death. For others, the crossing proved to be a huge struggle, one that continued to resonate with them through a lens of anger and unfinished business.

For one mother, this crossing was a protracted experience that took extensive time, as the doctors firstly attempted to save her child's life. As she described it, they had "overcome that bit", and there was subsequent hope for her child's recovery through discussions with the team of the possibility of a rehabilitation process. The uncertainty she experienced is contained in her description of the impact of these constant discussions with the medical team:

"We're gonna do this next but this might happen" "we're gonna do this next but this might happen, you need to be prepared for the worst at every time". And we were desperately upset ..." (Par013)

However, despite what could be perceived as warning shots from the medical team to prepare the family for the possibility that recovery would not happen. This mother describes her outrage that the introduction of that possibility of her son dying only came as an aside to a conversation about the risks of surgery:

“So yes, just before the surgeon brought him to theatre they told us that he might not survive the surgery, so was that preparation for end of life? Absolutely, like a big WHACK in your face, having said goodbye to him in his bed that morning ye know, so yea. And then he miraculously, I suppose, did make it through surgery ...” (Par013)

This sequence highlights the challenge for parents in absorbing the fact that their child might die. While it appears that the team were trying to be cautious in their approach with parents by having a discussion about the possibility of death during surgery, this mother experienced this as a physical blow – “a big WHACK in your face”. It highlights the difficult experience of medical uncertainty for this parent which has been found to be an onerous and challenging experience for parents of serious ill children (De Graves & Aranda, 2008). Indeed, Davies et al. (2008) suggest that this prognostic uncertainty may in fact be a barrier to parent’s ability to recognise end of life.

This confusion is explained by Kars et al. (2015) as parents’ struggle between “preservation” (the avoidance of death by sustaining life) and “letting go” of their child. In this research, parents expressed that their inability or unwillingness to accept that their child’s life would end evolved from their wish not to give up on their child. In this study, one mother spoke about the shock of understanding that the team no longer believed that active medical treatment was in the best interest of her son, with her declaring to the team to “give him a chance!”. Other parents recognised the complexities of “not giving up”, of trying to find a balance of medical intervention that gave their child every chance of life, while at the same time not putting them through unnecessary suffering. This parent explains:

“We have to keep going, we have to fight for him like, but you’re also going “is this cruel?” like you are like kinda going “what’s the best thing to do here?” it’s always in the back of your mind like you push it out like.” (Par005)

Parents who can recognise the impending death, however, were able to be present to their children’s deaths in the way that they wanted to be, despite a sense of panic among the extended family. For one mother, being able to work through her own feelings of uncertainty about the appropriateness of the care pathway for her child meant that she was able to accept that there was no longer a choice about her child’s medical outcome,

and to be psychologically available with her son as he died. In addition, this processing of her uncertainty, allowed her to share this with her family so that they too could recognise the importance of a quiet and calm death for her son.

“It’s like everyone was so shocked ye know [crying] because [...] more people like kinda would kinda die more slowly over a few days or maybe a few weeks, it was a shock ye know. [...] ... But em it was, so everyone was clearly panicked, agitated it wasn’t calm like ye know, the room wasn’t calm, so I remember thinking “if ye’s all don’t buck up I’m going to have to ask ye’s to leave” [...] because this is it like! [crying deeply] [silence] So ... I think they all did calm down a bit cause they all wanted to be there ye know.” (Par011)

Discussions about “Do Not Resuscitate”: Parents’ second key experience during this time was the discussions that took place between themselves and the medical and multidisciplinary team about Do Not Resuscitate (“DNR”) orders for their child. Turner (1967) reported that, for individuals going through a liminal process, “Instructors” can be identified. Turner (1967) believed that the relationship between the Instructor and neophyte was one of authority, whereby the neophyte deferred to the authority and wisdom of the instructors as “the personification of the self-evident authority of tradition” (Turner, 1967, p. 100). As can be seen in the following passages, parents were very grateful for the knowledge and wisdom of the teams that they were in contact with. However, due to the nature of their relationship with their child, they questioned medical opinion as absolute authority, thus adding to their confusion about the best way forward.

Parents highlighted the challenging nature of the discussions that took place in relation to the appropriateness of continuing active treatment. Previous studies have highlighted the fact that, in children’s palliative care, the decision to cease active treatment is often made very late (McCallum et al., 2000), frequently as late as the last day of the child’s life (Drake, Frost, & Collins, 2003), and can be influenced by the parent’s social and economic background (Hileli, Weyl Ben Arush, Hakim, & Postovsky, 2014). However, as Zaal-Schuller et al. (2016) brought to the fore in their research and as identified by parents in this study, parents wanted to be consulted about and central to the decision making about their children’s future care. For the parents in this study, however, the discussion about DNR was a key element in their development of understanding of their child’s medical pathway. These discussions were not always straightforward or understood by parents. Indeed, parents, when asked, often recognised that these

discussions had taken place earlier in the child's medical pathway, but also reported that they didn't remember explicitly what was said, other than agreeing with the medical team that their child would continue to receive full medical treatment. Ricoeur's (1984) concept of the phenomenal temporality helps to develop an appreciation of parents' thinking that the previous discussions of DNR, when, in their experience, a child was relatively well, were a confirmation of the decision to continue active treatment, rather than the beginning of a process of introducing a palliative care approach. The following quote demonstrates how this parent's understanding that her child would not survive evolved as information on her lack of response to intervention emerged:

"... she admit her in the hospital .. and then we had a meeting with [consultant] and [paediatrician] cause they were saying it wouldn't be good for her to take her to the ICU and pass the tube [for intubation], it was the first time she had the tube on. [...] And ... they said it would be hard for her to fight again and to suffer like everything again, and we had a plan not to pass the tube, just to have the [oxygen] mask maybe. [...] The ward, they didn't want to take her to the ICU again but they had to take her and she had a mask on ... but it wasn't helping her that time, it was like she was very, finding hard to breath and em. They used to work before but that time it didn't I think. [...] Around 3 or 4 in the morning they took her to the ICU and I came home in the morning and I rang the nurse and she said its not working this time, she hadn't improved. And ... we still say like not to pass the tube even that time cause she was very tired yea and the doctors said it might be her last day." (Par010)

Not all situations described were straightforward, however, particularly for this parent when she perceived that the medical team's recommendation for DNR as the team not being on their "side":

"But like the thing with ICU and I, that been explained to me by [consultant] eh she had ye know an issue around [child's] quality of life and stuff and ye know when I had to fill out that form and where you have to decide if you want to resuscitation or if you want ventilation. [...] Em [consultant] didn't think it was the best option for [child] so she wasn't on my side of the page there either. " (Par011)

Indeed, for some parents, the physical recognition that their child was dying was just too difficult to absorb, making any introduction of a discussion about DNR very difficult.

“Yea I mean, looking back ye know, yea there was lots of obvious clues but em you just don’t want to accept it, you just ... like” (Par0015)

The Introduction of End of Life Care with the Medical and Other Team Members: A third key experience was identified in which parents are able to recognise that their child was dying and understood the move to EOLC. These discussions highlighted the decision to implement full palliative care and the complexities that are involved with this for parents. Parents identified a clear pathway for moving to and then implementing palliative care.

For these families, the move to EOLC came after numerous meetings and discussions in which the latest medical information was introduced and medical opinions were shared. However, the implementation of a palliative care approach was not always straightforward, bringing with it difficulties and challenges that can be a feature of child’s EOLC (Hain et al., 2012; Bjork et al. 2016). For one parent, this was about questioning the palliative care approach and its appropriateness to their child’s situation:

“I just felt like “am I fighting enough for him?” constantly I was going like “should I be going saying “no”, you are doing the surgery like?”. Because I know some parents do that and then I’m like “Oh” I just didn’t know, I was just questioning it so much and then because it was so nice for him to be just left alone [...] instead of the worry of them doing surgery on him.” (Par005)

For another father, the lack of recognition of the meaning of his daughter having a palliative care approach was deeply associated with his not wanting to face the fact that his child would die. This lack of recognition extended even to him not assimilating the meaning of having the hospice care team attend his daughter each night. As he explains:

“cause I knew she was really bad, I suppose there was constant denial, or maybe I am, in constant denial of the inevitable, maybe I just didn’t want it to happen. Sorry [crying] [...] I obviously didn’t want it to happen.” (Par0015)

In this section, I have highlighted the key experiences of parents in the liminal space of their child’s EOLC and how they managed to come to recognise that their child would die. These experiences demonstrate the crossing of the liminal landscape, from a belief

that it is more appropriate to continue active care of the child, to a position that it is more appropriate to accept that they will die and provide comfort care, is full of challenges. This journey was fuelled by parents' oscillating concerns that they should not give up on their child and wanting to do what was best for them.

ii. Creating Trusting Relationships with Staff: Within the liminal space of EOLC, parents discussed the need to build a relationship with the health care professionals who occupy the liminal space of the hospital.

Parents identified three sub-themes as they discussed the relationship that they build up with the staff who are caring for their child: i) building relationships with hospital staff; ii) differences with staff; and iii) parents' empathy with staff.

Building Relationships with Hospital Staff: The first sub-theme described by parents was their need to develop a trusting relationship with the staff who were caring for their children. Parents reported that they felt that being respected by the staff and developing a trusting relationship was a critical part of their experience of this dying world.

Parents were able to identify key elements of this trust building as staff: seeing the situation from the parents' perspective: anticipating parent's needs: and encouraging parents. They also identified with the function of staff as Instructors (Turner, 1967) reporting that this was based on the medical authority of the doctors and the respect that the medical teams showed to parents. Another example parents provided was trusting nursing staff to respect their wishes in relation to the manner in which their child should be cared for, with one parent describing their views as being "very much on that same page" with the staff.

Parents reported that being able to talk to the staff about their child's personality and history was critical and being able to "show off" their child and be proud of them, even in their dying days brought them a deep comfort. This father reported that

"we brought a USB in and we played it in the family room in ICU and it was good for us to show them [child] ... living ..." (Par008).

In addition, the building of this relationship allowed parents to rely on staff to help them by containing their anxiety and by acting as a guide, described by this parent as “handholding and they were there for support” (Par003).

In addition, staff provided reassurance, even if that reassurance was confirmation of deteriorating health, as this parent describes:

“So it was very useful because [consultant] was able to explain to me [...] So ye know she was able to tell me that his body has been through so much over the last kinda six weeks [...] Without, he didn’t get a huge break where he has a chance to fully recover [...] And she just said his body can’t take any more, it’s just taken so much that he doesn’t have the fight left, he physically can’t, he couldn’t do it, he’d been through so much, ye know his little body just gave up [...] So even her telling me that make me feel a little bit better [...] So it was reassuring to hear that.” (Par011)

In addition, parents talked about the human side of the staff they encountered, the “human touch”. For one parent, it was the staff meeting them at the front door of the site as they arrived from their local hospital after their son was transferred by ambulance, particularly important for her as she reported she was in a physical state of collapse. For another couple, they felt that staff saw their job as more than just “working”, but that they carried it out with a “human touch”.

“Cause we had another lady [nurse] [...] so she was like ye know they must see this thing happening way too often in there but then just human touch or just the eh you could see them filling up and they’re not just ... like its not like a production line”. (Par008)

This “human touch” led to gestures by staff that exhibited that deep caring for the children they were working with, as this parent demonstrated:

“Yea I remember [...] one of the nurses showed up for her shift and she had brought a detangling spray and a comb and she just said, “if you don’t mind, we can take [child’s] hair out of the ponytail and I can maybe just try to comb it out a bit” and I just thought like just little touch like that ye know it meant so much.” (Par009)

Indeed, the strength of those relationship for parents was signified by them remembering the names of individual staff members and often pausing in the interview to ensure they got it right, in what appeared to me to be an act of respect for the staff member and to emphasise the importance of that relationship. Discussions of this level of human connection between parents and staff at EOLC were not found in the literature review.

Differences with staff: For some parents, however, difficulties existed in the staff/parent relationship, particularly when there were differing opinions about the most appropriate care plan. As has been seen in the literature review, challenges can arise between parents and staff in relation to making decisions about future care for the child due to medical complexity (Hammes et al., 2005; de Vos, et al., 2015) or difference of perspective (Kars et al., 2015). For one mother in this study, it was about the consultants involved in her child's care not believing that intubation was in his best interest, resulting in the belief the consultants were not giving her child the best chance of survival:

"But then when she walked in with em [consultant] I thought to myself, "something's after happening and I'm after missing it" but between the two of them they decided that they said "Yes he hasn't been intubated yet, but the way he's going he is going to need it" [but] they felt in [child]'s best interest it wasn't the right thing to do to intubate, they felt." (Par011)

This experience was very distressing for the mother who felt that the consultants were not giving her child the best chance to survive.

For another mother, it was an encounter just before her child's possibly life-saving surgery that distress her, when the consultant questioned the decision to go ahead with the procedure:

"it was the [consultant], I can't remember her name but she was like, she came, she stayed in the room and she said to us "are you sure you want to do this?" and I remember like it just totally freaked me out, I panicked like, and I was just going "what's the story with people in this hospital?" [nervous laugh] like she just panicked me and I was just like "why" and I was like "no we have to do what we can for him". (Par005)

For one mother however, she was left with a grave concern that the actions of key staff and the decisions they made, gave her son the message that there was no hope in his situation, and that because of this, he may have gotten the wrong message about his survival when staff took him out of his wheelchair, and returned him to bed:

“And it’s just like “why did they do that”? ... I would have just left him in his chair, and never taken him out of it again. He just knew it was his chair. Maybe did he think? I dunno ... Did he think but couldn’t say “I’m back, I’m back” but then “no, back in your bed now”? (Par0013)

The seriousness of this gesture played on this mother’s mind since it occurred, and she wondered aloud to me later in the interview if it has actually contributed to her son not believing he could survive and therefore not working to survive.

For other parents, difficulties emerged regarding the legal requirement arising around the time of their child’s death. Parents often became confused in situations where the kind and trusting staff, who had been in the position of Instructor, now became responsible for introducing legal aspects of their child’s care that were, in their opinion, incongruent with the kindness they had previously demonstrated. This highlights findings by Griffiths et al. (2018) that the involvement of the Pathology Team in these conversations with families whose children have died could benefit parents in understanding these procedures.

For the parent below, on-going trauma was caused from his experience of first seeing his child with all the tubes and equipment still attached to her after she died. While this is a legal requirement in the case of an accident, he clearly describes how traumatic this experience was for him:

“And you could be having good day or week or month and it just brings you straight back into that very picture ye know what I mean, so to make it short and sweet, it’s like say, if if I think ... em ... I know there does be a lot going on or whatever I dunno if everything can be removed for medical reasons or whatever [...]. It has to be left in place but eh it is something that haunts a parent, deeply, and em I just think I was sort of like not to the hospital’s fault but it’s just the way things were that day. I was like ... I em [tut] with the trauma of what happened [child] that day it was just like a horror scene to be honest with ye” (Par012)

Again, this extract emphasises the importance of the parent being prepared for how their child will be when they see them after they have died (Davies, 2005) especially in the case of a sudden death (Garstang et al., 2014).

Other legal requirements such as the need for a post-mortem examination and/or organ retention during that post-mortem process can be distressing for parents. For this mother, she felt that the possibility of organ retention was not well explained to her, adding to her trauma in an already difficult situation. This lack of understanding led to one of the more difficult experiences for her in her child's death:

“the thought of her coming back home to us without actually having her brain was just it was just so surreal, it was so hard for me to comprehend, I felt very angry, like she was in a car accident, we know what happened, we know what caused ... [nervous laugh] the injury, like what further testing needs to be done, why would they have to retain that ye know you kept these horrible images in your head of those horrible processed and it just it really knocked me sideways because I just had no idea.” (Par009)

While these experiences were, happily, in the minority among the parents I interviewed, the depth of the emotion that remained attached to them at the time of interview was remarkable, as noted in each of my post interview notes. It highlights the complexity of the relationships within this liminal world where parents and staff are brought together through crisis, often without any pre-existing relationship.

Empathy with Staff Doing a Very Difficult Job: The third sub-theme identified by parents was a sense of empathy with staff doing a difficult job. In addition to acknowledging the difficulties they experienced, parent recognised and empathised with the difficult job that staff undertake in their care of dying children. For one couple, they spoke about how sensitive staff were for not asking them to leave the room, despite the fact that, from a nursing point of view, it would have been easier to care for the child without parents at the bedside all the time. Staff's consciousness of parents' limited time with their child meant they were willing to make that extra effort. Other parents recognised the efforts that staff made to care for their child, and for them, and acknowledge the emotions that staff experience in caring for their child. For one mother, it was about seeing how upset the staff were that her child died and the humanity of the staff in her child's care team:

“Cause even like eh [nurse] ... just losing it, not losing her composure but like great to see her lose her composure, like not her composure but her professionalism by saying “fuck the world”, things like that, it really got really got to her and ... it was nice to see that kind of real person there rather than ye know everyone out of their depth.” (Par008)

Indeed, parents recognised the connection that is forged between themselves and the care team through their mutual emotion experienced in the death of their child and spoke about the demonstrations of those emotions as providing them with comfort, as the next quote illustrates:

“There was one of the nurse who, who had been just as kind and pleasant as any of the nurses but maybe a bit more quiet em and at one point I saw her em take a tissue out of her uniform and walk away and I could hear her crying behind us, and ... that, that was really powerful because it was like yea it’s not just us losing her, like the world is losing this little girl right now, this girl who has been caring for her for the last few days is losing her and she is so stuck in this moment that she can’t just stand there stoic and let the emotions out later, like it had to come out.” (Par009)

Indeed, this parent’s statement highlighted the idea that this parent felt she was not alone in her bereavement, that her child’s death had meaning in the wider world, reflected in Widger & Wilkins (2004) finding that the death of a child is a loss to society in general, emphasising a social constructionist perspective on death (Payne, 2009; Neimeyer et al., 2014)

Within this theme, I have explored parents’ experience of the development of their relationship with staff and demonstrated how these relationships come to be an intrinsic part of parents’ experience of EOLC. In the main, this relationship was based on trust. For some parents, however, this was not the case, and they vividly described their concerns about situations where they were not in agreement with a care plan, or an intervention for their child. Parents also took time out to empathise with staff doing a difficult job and the constant decisions they had to make to balance their needs as staff members with parents’ need to be with their child.

iii. Finding a Way Through the Liminal Space: Critical to all parents' experiences of their child's dying was the process through which they came to understand the liminal space of children's EOLC. They clearly spoke of how there was no clear path to follow, but that they worked to absorb the information being given to them, using that information as a bridge to a deeper understanding of their child's situation and using the lens of their known world to interpret and understand the landscape of the liminal space in which they found themselves.

Absorbing Complex Medical Information: Within the *first sub-theme* parents outlined the process of absorbing complex medical information as they began to understand that their child's life was at risk and their prognosis was compromised. Within this area they identified a number of critical elements - how a parent received information, what they experienced as elements of good care, the experience of having challenging conversations and difficulties in communicating.

For some parents, their orientation to this liminal world of their dying child was sharp and abrupt, as they experienced staff in their local hospital emphasising to them how serious their child's situation was, resulting in the need to move to the site hospital to have any chance of survival. This mother experienced the multiplicity of questions and complex messages arising in that situation as confusing and distressing.

"they said "he's .." and the nurse came, the doctor came and she says "do you realise how serious [child] is?" and "we're going to get him better" and I em "fill out a few forms" and "where is your husband?" and "do you understand what we are saying to you?"" (Par006)

For others, they recognised that staff were making efforts to be clear with information but were also unambiguous. For one mother, this occurred because three medical consultants attended the meeting in which they were told her son would not survive, allowing parents to be provided with information and ask questions from multiple perspectives. For another mother, clear information was provided, but she also felt that, while her questions were being answered, the medical professionals "held something back" so as not to overwhelm her with too much information at the same time. She reported: "they don't want to crush you either ye know ".

Reading the Cues: The *second sub-theme* highlights prompts or clues parents found that allowed them to develop a deeper understanding of their child's situation. For parents, these prompts often came in the form of observing that staff were concerned for their child and they identified a number of incidents of non-verbal communication that indicated to them this concern. They identified the use of quiet rooms, non-verbal interactions, or the presence of the Gardai¹⁷ as prompts that the situation was very serious.

For one mother, it was the reaction she received from the ambulance care team when she arrived at site hospital after being contacted about her son's accident. This encounter prompted her to surmise from her interaction with the medical consultant who was at the scene that he would have reassured her if he could and confirmed her suspicion that her son was gravely ill. For another father, it was the tears he saw in the eyes of the paramedic with whom he had travelled in the ambulance from their home to the local hospital, as he explained:

"Like then I was the only one on the corridor and then like I was given a chair to sit down, that's when I spoke to the paramedic, and saw the tears come down and like, I may even have said "why are people looking at me" and I remember I was bawling [crying profusely] on the corridor where I was standing and my head was against the wall." (Par008)

For another parent, the site hospital staff calling the Gardai to help escort them the last few miles of the journey because they had gotten lost, indicated the urgency of the situation.

"By the time the Guards [Gardai] came, I knew it was very serious." (Par006)

Another father used the monitors in his son's PICU room to begin to understand his son's critical condition. Interactions with staff before formally being told the child was dead helped prepare parents for the seriousness of their child's situation:

"Basically she was saying, without saying that [child] was dead, but that [child] was never going to come back like without say it." (Par008)"

¹⁷ An Garda Síochána, the Irish Police Force.

Turning Points: The *third sub-theme* describes turning points where parents began to recognise that their child was dying. Parents identified different ways that this could happen including: consultants managing their expectations through the provision of realistic information about their child's health; the care team providing prompts; having physical contact with the child at their bedside; and their own changing emotional reaction being with the child. All of these factors allowed them to develop a deeper understanding of their child's health status.

In an interaction between one mother and her child's consultant, the parent clearly identified that the consultant did not provide false reassurance that everything would be alright with her child, with the consultant advising caution in her expectations for her son:

"he was the consultant and he but he was really like I was going "ok he's doing good isn't he?" and he was kinda like ye know... "you just have to be really cautious here"." (Par009)

As this mother explains, being physically present at her son's bedside for the first time after he became acutely unwell, helped her to begin to absorb the information that her child was going to die:

"I just went straight up to [child] [pauses to cry] all I saw was him [crying deeply] ... And I feel like that was the first time, it felt like I was even to feel he was going ... [crying deeply] I just sat, like nobody stopped me, I just sat on the bed cuddling his face [crying deeply]." (Par007)

Contextualising Information Through the Lens of Family Belief Systems: This *forth sub-theme* encompasses parents' processes of gradually contextualising information through the lens of their own or their family beliefs and values. Parents struggled to understand their child's impending death within the context of their own lives, their own previous experience, or through their belief systems and their values. In order to understand the child's prognosis, parents used various ways of improving their understanding; asking questions of the medical team; taking hope; experiencing an existential crisis; expressing different opinions about the care plan; and finally making choices about their child's care within the context of their forthcoming death.

For some parents, this meant questioning doctors about the information they were providing about the child's care. For others, this questioning could be quite forceful, believing, for example, that the doctors might choose to stop active treatment too soon.

“And I remember telling her she was wrong, she didn't know what she was talking about just sheer panic and denial and I said “you don't know what you're talking about” (Par011)

However, for some parents, being involved in decision making about their child at the end of their life raised deep existential questions in relation to the parameters of what was appropriate:

“so for me what was ethical, what was right, I knew what the end road was going to be, but when was the right time?. So in my mind, ye know, is this hastening the death, is it, is it em is it like assisted suicide ... Is it, is it natural, what's allowed?” (Par001)

Interpreting the information that they were provided in the context of their values and beliefs facilitated them to bring clarity to the complex and ambivalent liminal space they found themselves in. For many parents, their struggle to find their way within the liminal space of the hospital allowed them to place their child's impending death within the context of their known world, enabling them to cross the threshold, recognising the reality of what they were facing (Andrews & Roberts, 2012). This relocation of their experience helped them to then make decisions about what they wanted to do, and how they wanted to be together with their child during their final hours.

Some parents in the study clearly demonstrated that they had embraced the liminal space and fully understood what they were facing. For three sets of parents in this study, this was through the process of being altruistic in their child's death by agreeing to organ donation, “like trying to hold onto any bit of comfort and good...” (Par009).

For others, it was the decision to include their support networks in those final hours for others to understand how difficult it was for these parents to lose their child, for the family

“to see him ... and to understand what it is like to see him in that kind of ... environment and to understand how awful it must have been for us to have to look at him like that.” (Par007).

And for some parents, together with other important people in the child’s life, ritualising their goodbyes was very important. This was through the attendance of key family members at the child’s death including siblings, aunts and in one case, the child’s teachers.

“ye know, they [siblings] read, they had all the things that they remember about [child], ... so they talked about what they had for him ye know because he wasn’t awake [crying]. So that was very good. Yea I think that that was very good for them, they still talk about that ye know and that they did that. “ (Par002)

“We had time and I says just “[sister] turn on ‘You’re my Sunshine’[song] on the thing” they had all fairy lights and everything and lovely blanket over [child] and “oh” I says “we’ll have that song at the funeral” and making plans with the kids it was very important with [sister] and [brother].” (Par006)

“and they said “we don’t know, she could be a couple of hours, she might be a couple of days”. [...] her teachers came over, ... they sang [silence] [crying] God! [crying deeply] [deep sigh] [silence] [deep sigh] [silence] they gave her little presents and stuff [whispering, crying deeply] [silence].” (Par015)

For other parents, it was the physical connection with their child as they died. For one parent, laying her hand onto the child’s chest as they died, so they could feel the last heartbeat was important.

“So they let both sisters come in and we sang to her, I held her, and it happened quite quickly, I actually could, my hand was over her heart, so I felt the last beat.” (P009)

For others, this meant having a memento of the time they said goodbye by taking a screenshot on their phone of the date and time so that they would never forget.

Telling Others: The final sub-theme that described how parents went about finding their way through the liminal landscape was through telling others of their child's deteriorating health. This external articulation clearly demonstrated that parents now knew their child was going to die.

This was not an easy process, as identified by one parent who reported she became "hysterical" on the phone when she had to share the news with her mother that her son was fatally ill. In this extract, she equated telling her mother with a "job", a description that articulated the burden she felt in doing this:

"So the next day I had the job of ringing my mam and dad and em [tuts] I rang and I was hysterical on the phone I couldn't even tell her what's after happening, I ... couldn't even, it took me a while and she was screaming "why didn't you tell me what was going on?".“ (Par011)

This father, experienced difficulties knowing what to say to his wife on the phone when he needed to explain to her that their child was critically ill, without scaring her too much, as she had an extended journey to get to the hospital. A senior nurse provided him with some simple language to use with his wife, as he explains here:

"Cause like [exhalation of breath] you don't want to be ye know how bad it was over the phone to [spouse], so she [nurse] just said "it's serious, you have to come down, he's not well" and that's and that's what I said, so probably the worst phone call I've had to do in my life, probably the worst thing ever to be honest." (Par008)

This process for parents, of becoming aware of the information about their child, of trying to absorb this information within the context of their own lives and belief systems, and then recounting the fact of their child's ill-health and death to other, illustrates the process of wayfinding through the landscape of liminality, to try to journey across to a place of understanding. This sequencing of the development of understanding by parents was not reflected in the literature reviewed.

5.2.3. Theme 3: Emerging from Liminality

This theme describes the process for parents as their child physically dies, and the time immediately after the death. Parents also talked about the importance of the continued contact with the hospital as the third phase of the liminal experience that took place and they began to face the world without their child. As Griese, Burns, Farro, Silvern, & Talmi (2017) suggest, using spontaneous opportunities to promote positive adjustment and work to prevent possible future complications is a key way to support families who lose a child and can reduce the sense of isolation felt by bereaved parents (Price & Jones, 2015).

i. Memory Making: Parents identified a number of activities that they undertook during their child's EOLC and death that helped them to create memories with their child and to create physical connections between the EOLC and their bereavement journey after the child died. Such activities have been found to be an important part of a parent's bereavement journey (Goldstein et al., 2020; Meert et al., 2009).

Spending as Much Time as Possible with Child: All of the parents in the study spoke of the importance of spending time with their child during EOLC, reflecting findings within the extant literature that remaining close to their child was a very important experience for parents at this time to honour their relationship (Butler et al., 2018; Darlington, 2017; Meert et al., 2009). All of the parents in the study, except one, were with their child when they died, mirroring Wijngaards-de Meij et al.'s (2008) findings of the importance for parents of saying goodbye to their child. The parents in this study deeply appreciated that the hospital allowed them to spend as much time as they wanted, without restriction, lying on the bed with them, "because they knew this was our last chance to..." (Par001). For this mother, this very simple process allowed her to reclaim her child, to be his parent again "and that he was mine again" for the short time she had left with him.

For many families, the ritualisation of spending time with the child before death was extended to key family members as described by this parent:

"And my brothers came up [deep inhalation of breath] an ... to us Wednesday evening and they brought their oldest children and their wives on the Wednesday and then they came up on Thursday just we just can't say how wonderful the whole thing was ... [...] because we could bring up people, they came from

[county in West of Ireland] up to see [child] on the Thursday, [...] before we turned off the machine, we turned off the machine on the Friday, [...] yea, that was so nice. “ (Par006)

For one parent, the critical importance of that time was recognised in the context of her child’s particular circumstance, where she was transferred to the site hospital to allow for the very small possibility that that her life could be saved, but more likely to allow her family to have time with her before she died, something that would not have been possible in the local hospital as they did not have the appropriate facilities. In this extract, her mother explains how important this time was in commencing her bereavement journey.

“I can’t imagine having just showed up to [local city hospital] and being told like “your child had just died” [...]. We had time to to absorb what was happening and em ye know the the staff in the ICU in [site hospital] went above and beyond to do their absolute best for us.” (Par009)

For other parents, it was the opportunity to spend time with their child as they died. For this mother, it was being so physically close that she could monitor his last heartbeat and understand for herself that her child had died:

“I think he lasted about twenty minutes or half an hour, even now I still can’t remember exact em ... but ... em ... [crying] I was lying beside him on the bed, I had my hand on his chest ... em ... I don’t know what I noticed first [speaking through the crying] his heart stopping or his breathing stopping, cause his breathing was quite em [sniffles] quite noisy, ye know [...]. I don’t know what stopped first, or did they stop together I don’t know, but I remember I could feel his heart had stopped [sniffles] and then so that was it.” (Par011)

For this next mother, it was holding her daughter while she died, in the same position that she knew comforted her in life, so that her daughter could be “happy” as she died:

“And I always used to hold her on this side [indicating right arm] she never used to sleep on this side [indicating left arm] [...]. And that day I was holding her on this side but my hand got tired cause I was holding her I think all day [...]. And I just realised that was holding her on this side, she she doesn’t like this side [...]

we managed to move to this side, [...] and then just after a few minutes she passed away. I felt like I think I did a good thing maybe cause she was on this side and she was happy maybe.” (Par010)

For both parents, being with their child as they died, as they had been with them when they were born was a critical part of this journey. One parent described it as the “circle of life” to have held your child and cared for them in the first minutes when they were born, and in the last minutes as they died.

Doing Regular Parenting Tasks: Within the interviews, there was clear evidence of how strongly parents felt about being involved with or undertaking ordinary tasks with their child, tasks that they would undertake often at home as part of their parenting and caretaking of their child. Butler et al.’s (2015) meta-synthesis of the literature on the experience of parents whose children die in a PICU, emphasises the importance of this role in de-medicalising the death experience. For parents in this study, this meant undertaking parenting tasks of lying up on the bed, cuddling their child, sleeping with their child, dressing their child. Parents were able to capture the sense of being a parent, by undertaking rituals that they would always do with their child before they were dying.

For one mother, the recollection of undertaking the ordinary parenting tasks was the point at which she was most upset during the interview. This extract highlights how this mother fought her deep emotions during the interview to explain how strongly she feels about being allowed to undertake these ordinary parenting tasks with her child for the last time, clean his teeth, lie down beside him, and, with the help of the nurse, to put her hand on his face during the last morning before he was extubated and died:

“I didn’t sleep at all for the three two nights, I got up at 6 o’clock and I could wash his teeth and I could [whispering] [inaudible] [crying] [...] that’s all [loudly] that’s all very important [continues crying] [...] having all that time, [...] the nurse would help ye to just don’t ye know for him to feel ye [crying, indicated hand up by the face] [...] Very very very important” (Par006)

In addition, some parents found it important to complete these regular parenting tasks after the child died, including “hugging and holding”, “washing and dressing” their child.

Special Events with their Child: For some parent as the situation permitted, it was very important to undertake activities that were outside of the care setting. For those parents whose children were cared for at home before they died, it meant

“a little walk was around the village like, and down the beach, we did a little housing estate crawl!” (Par003)

For others it was taking their child out of the hospital for a special family occasion. For one father, fulfilling his daughter’s wish to go to a musical, despite their daughter being critically ill in hospital, was especially important in their creation of memories as a family before she died. After lengthy and detailed negotiations with the hospital, she was allowed to go on release with her family with full medical back up in case of an emergency.

“So we went to [tuts] to the [theatre], with oxygen bottles, and oxygen bottles, in case one failed, there was another one, and medicine, and medicine, and medicine, and medicine [...]. And em, [tuts] [silence] [crying] [...]. Big posh night out!” (Par015)

Hospital Initiated Memory-Making Activities: In addition to the memory making activities initiated by families, the site hospital offers, if appropriate, to facilitate a number of memory-making activities for families whose child dies on site. Two of these were mentioned in this research:

- *ceramic hand and footprints* which are then cast and fired by a local artist and gifted to the family by the hospital. This process had resonance and meaning for parents. One parent reported that it “meant a lot”, while another reporting that it was “amazing!”.

- *photographs:* the hospital clinical photographer can attend and take photographs for the family during EOLC if they wish and how they wish. The importance of those photographs is outlined by these parents:

“Par008: We obviously took photos of [child] when he was unwell and ye know ... I know those pictures are there, I don’t look at ‘em, but I like the fact that they are there, because they’re there as a potential connection, to reconnect

Par007: And to remember

Par008: Yea and to remember, again that fear of forgetting, ye know what's it's like, ye know, tears are good and so tears equals connection so I know those pictures are there and I can use them when I need to use them"

For one family, a photograph taken by the clinical photographer during EOLC was actually the only family photograph they had before the child died and was shown to me as having pride of place in the family's hallway when I visited to do the interview.

It was of interest to note that parents did not mention the "memory boxes" provided by the site hospital to each family of a child who dies. These boxes contain bereavement information for parents, and other items to memorialise their child, as well as it serving to gather important items of clothing, wristbands, photographs and cards that might have been at the child's bedside as they died. In addition, parents made mention of taking a hair lock was very important as a physical connection to their child. All of these findings reflected findings in the extant literature about the importance of memory-making and having physical items to connect parents with their child after they have died (Currie et al., 2016b; Meert et al., 2009).

Child's Legacy: The importance of publicly recognising the meaning of the child's life through rituals immediately following the death was discussed by a number of parents, and, for them, was reflected in the people who travelled to the site hospital to visit the child while they were dying or to see them immediately after their death. For other families, the importance of the wake was identified. These activities ritualised the legacy that the child left behind (Moxley-Haegert, 2015). One mother reported the importance of the ritual of taking her son to be waked in her parent's house. "Yea he was laid out there and so everyone could see him yea". One mother, as a non-Irish National, was unfamiliar with the traditions of an Irish funeral, yet this experience brought her great comfort in the effort that everyone made to mark her daughter's life. She reported:

"I don't think it would affect me that much, but just ye know older people that I've never met in my life in their Sunday best standing outside in the cold for an hour, just to say "I am sorry for your loss" and [...] that was really meaningful." (Par009)

In this section a range of spontaneous and planned activities and rituals were clearly identified as helpful in creating important memories and facilitating parents to begin to incorporate the death of their child into their lives.

ii. Post Bereavement Contact and Support: Within their discussions, parents regularly referred to the bereavement contact and support that they experienced from the site hospital after the child's death. Parents identified how important this contact was for them, in revisiting their experience of their child's EOLC, to clarify and further understand the experience that they had been through as highlighted by Griese et al. (2017). Indeed, Kochen, Jenken, Boelen, Deben, Fahner, van den Hoogen, . . . Kars (2020) in their systematic review of the literature on HCPs provided bereavement support, emphasise how hospital-based bereavement interventions can be helpful and supportive to bereaved families.

Post Bereavement Meeting: For some parents, this took the form of an arranged meeting with the consultant in charge of the child's care and facilitated by the medical social worker who is allocated as the post-bereavement link person with the family after the child's death.

“Just to say [...] the after bit as well, we obviously went back for a post-mortem [...]. And [medical social worker] and [consultant] were there and that was really important for us. I felt like actually that was a turning point in our journey in it. I felt like he [consultant] was very human that day. [...] I found that he was very very human that day, I remember talking to him about the doctor [meaning GP] and he should have known and all this and he said not if he had lived across the road from [site hospital], and in the end he actually got up and gave me a hug and I thought do ye know what that was very, that was very personal as well So I feel that any experience even after like ... and I know that we can go back.”
(Par007)

For some parents however, making the decision to attend the hospital for this meeting is not straightforward as it took some time for them to feel emotionally ready to come back to the hospital.

Post Bereavement Phone Calls and Home Visits: At other times, parents talked about the post bereavement phone calls and the home visits provided by the social work team – “all that means a lot” (Par006).

For this parent, having phone calls with the medical social worker immediately after her son’s sudden death helped her to try to understand her world which was in turmoil.

“She was the first person that I had ye know and like I talked to friends and all the rest but nobody knew about anything. And even for myself, like I felt like I just needed to know how to parent ye know, them through it ye know and [social worker] the first visit that she had ye know immediately put me at my ease to know, not that I believed her fully [laughing], because I think that takes time, I could trust my own instincts [crying] and that I could get them through it, that I still had ability to ... I felt so vulnerable [crying]... So she was a huge, an important support for me in those first few months, [...] And all that for those six weeks I felt that I was drowning [...] so for someone to confirm and just to be there and to listen and to, that was hugely important.” (Par002)

Meeting Other Bereaved Parents: For some parents, meeting other bereaved parents through the hospital’s Bereaved Parent’s Programme provided them with an environment where they could speak about their bereavement to an audience that was so willing to listen and empathise with them.

For one father, it meant that, despite reservations at first, meeting other bereaved parents became very important for him in his bereavement process.

“you do withdraw a little and you don’t want to just stop talking about [child] but the forum that that provided to actually talk passionately about [child] because you know everyone is listening because I listened to their stories and you feel like ye know each other’s child and you wish it was different circumstances that you met them [...]. And it’s like you give life to each other’s stories, to the stories of each child’s life.” (Par004)

Each of the activities outlined in this section represents a reaching out by the hospital to provide a bridge to parents in the early days of their bereavement. Having a link with the staff team that was created within the hospital during their child’s EOLC meant that

parents were provided with a familiar link back into the hospital. This allowed them to make use of the various processes that facilitated them incorporating their end of life experience, an undertaking that is so important in this phase of the liminal experience. This mother reflected this reaching out when I asked her for to clarify the delay in the time from her child's death to her return to the hospital for a meeting:

“Yea it was because, especially with me, it’s something I would have put to the back of my mind and in my own time, I would have fretted over it not knowing where to have go with it, where ye have little, little reminders coming at ye every so often which is good. [...] and its very good because ye can, ye get caught up in so much ye know, and ye might forget that there’s people there that are willing to help, and ye know you do need that little reminder.” (Par011)

iii. Community Response after Death: Some parents found that the immediate support provided by their communities an important part of their bereavement experience, while many remarked on how difficult it was for their extended families, friends, work colleagues and community in general to find a way to integrate the loss into their everyday contact with these parents. Parents spoke about difficulties that their local communities were experiencing in providing support to them a year and more after their bereavement.

For some parents, this was identified as a lack of understanding of the experience and subsequent avoidance of the individual as a bereaved person, for example, thinking that parents miss their children more on special occasions like a birthday, than other days. Parents reported that this meant they spoke less within their communities about their dead children, and that spontaneous opportunities for support and a “chat”, like neighbours dropping in, was lost. As this father declared:

“I just don’t talk about [child], Jezus, it’s not like a story anybody wants to hear [laughs while crying] unless you are in a situation like this.” (Par003)

In the end, however, this experience can cause serious distress for parents, which Szakolcasi (2009) would suggest presents the possibility of “permanent liminality”, where those who have not been through the experience of a death of a child, find it difficult to understand and therefore support those parents who have gone through it. One father describes this feature of his continuing liminal experience very clearly:

“because it’s like when that happens to ye, it’s like people they put up the shield, oh like “we won’t bring up his daughter to him anymore, we won’t bring up this we won’t bring up that”, and you feel like isolated from the world and you feel like everyone doesn’t give a feck like ye know what I mean and [...] like they don’t care like, anything. Its just like you’re sort of left like for yourself to deal with it where people thinks.” (Par012)

This experience for parents compounds their bereavement process as it can then be left to them to reach out and ask for that support.

“that’s so difficult to just pick up the phone and ask for help [...]. Yea like so you really just need people to show up with just show up and do stuff [...] because its actually still putting the burden back on you to kind of help yourself by calling someone to help you.” (Par009)

The difficulties experienced in accessing informal support in their community provides a context for the helpful support that the parents described experiencing from the site hospital.

This post bereavement contact and support allowed parents to revisit their experience of EOLC, and to gain more or clearer information about the cause of their child’s death, which parents found helpful. However, as noted, it can take some time for parents to be ready for such a meeting. For others, the supports provided through the memory-making activities before the child’s death stood out as critically important to parents, particularly those that were close to their experience as a parent before their child became critically ill, being with their child, and doing regular parenting tasks. In light of the difficulties identified by parents in their communities, remembering their child or taking about their death, this contact and support provided by the hospital appears to be of great value to parents, providing context to their bereavement in the very difficult first years after the death of their child.

5.3. Discussion

Within this chapter, the major themes emerging from the exploration of parents’ experience of their child’s EOLC were explored from the perspective of Liminality.

Returning to the definition of liminality as a threshold (Rallison and Raffin-Bouchal, 2013), the analysis highlights the transitions that parents experienced during this time. As Van Gennep (1903/1960) suggested, major life events, or rites of passage, including death, can be structured within the concept of liminality. In his development of Van Gennep's concepts, Turner (1969) described the process of these rites as having three phases: separation, margin (or limen) and aggregation. Undergoing a liminal process brings with its transformation (Stenner et al., 2017) or as Turner (1967) describes a "becoming". The exploration of the findings in relation to parents' experiences highlighted processes of transformation, both from a biological perspective (in that their child had died) and a social perspective (in that they are now a bereaved parent) (Braude, 2012). The experiences that parents described during the period of their child's EOLC highlighted their entry into that experience of liminality (Theme 1), their process of transitioning within the liminal space of the hospital (Theme 2) and the commencement of the integration of their bereavement as they begin to emerge from their liminal experience (Theme 3).

The experience of living in liminality within the bounded and structured space of the hospital was clearly described by parents. Van Gennep (1903/1960) believed that this middle or "limin" phase of the rites of passage was the most critical in the transitional-being's process. He believed that this transition was characterised by "a duration and complexity" that was in excess of that experienced by the first and last phase of the rite of passage (p.146). This period is characterised by a change in the everyday norms and ideas which the transitional being uses to understand both their physical and emotional experiences (Braude 2012). Throughout the discussion of these findings around parents' experiences, this transition can be seen as they make the move from the world they had known into a world where they grapple with understanding the complex medical procedures and discussions, and deal with the highly emotionally demanding process of coming to understand that their child will die. It is therefore understandable that Turner describes this process as a "becoming" (Turner 1967). For many, it involved the "reshaping" of identity characterised by "uncertainty and disorder" (Hogue 2006, quoted in McKechnie 2010) which is wholly evident in the experiences described by the parents in this study.

The second core concept of liminality is regarding the dimensions of time (Braude, 2012, Carter, 2016). Ricoeur's (1984) description of two different facets of time are helpful in understanding the complexities of time within the liminal experience. He describes firstly,

the *linear process* of time as it moves in chronological order; and secondly, the *phenomenon of time*, or the ability to understand our experience from the context of the past, the present and the future. Within liminality, these concepts exist outside of the conventional norms (Eaton & Hornborg, 2009) and are described as markers within the liminal experiences, providing boundaries and structure to an experience that is, in essence, uncertain and ambiguous (Leach, 1976; Kelly, 2008). In this study, parents describe how, for example, the process of understanding their child will not live can take both chronological time, in that some parents can come to a place of understanding, or of the phenomenon of time, in that parents, despite discussions with doctors or the introduction of palliative care measure, still have not grasped that their child will die and describe the death as “sudden”.

Within the liminal world of EOLC, Turner’s (1969) concept of “*communitas*” to describe the relationship that is developed in liminal institutions between its different occupants is very useful in understanding the complex relationship that develop within this situation. He reports that he favours the use of the Latin term “*communitas*” to its English translation “community” to highlight the social relationship which is intrinsic to this definition (Turner, 1969). Within the hospital, trusting relationships were often built up during the child’s last hospitalisation, for some parents with teams they had known before, but where their relationship became intensified, or with teams they had not previously known. This type of *communitas*, Turner (1967, 1969) refers to as “spontaneous *communitas*”, built on the relatively short time frame that is needed to make the decisions that are required. The importance of this “spontaneous *communitas*” is clearly seen as parents talk about meeting with and developing trusting relationships with the health care professionals caring for their child. Parents describe how they are dependent on health care professionals to provide medical information, to discuss their child’s care options, to provide support and possibilities to carry out their regular parenting activities, which were shown to be so important to parents.

For parents attempting to find their way through this liminal space the anthropological concept of “wayfaring” was useful. Parents spoke about how difficult it was to know what path to follow, concerned that they would be disloyal to their child. This process is reflected in Ingold’s (2000) notion of “wayfinding” as a way that individuals gain knowledge as they travel through liminal spaces (Andrews & Roberts, 2012; Chia, 2017). Ingold (2000) believes that individuals “know as we go, not *before* we go” (p. 229). Parents in this study clearly demonstrated this development of knowledge as they

journeyed through their child's EOLC. Indeed, Andrews and Roberts (2012) go on to state that what guides the novice or "initiate" within the liminal landscape is what they call "situated practices of wayfinding" (p. 9). Within the study, parents demonstrated the "situated practices" they followed or created in order to find their way through the liminal landscape of the hospital.

As parents began to emerge from liminality as their child died, and they realised that there now was no hope of survival, parental experiences can be compared to the third phase of liminality referred to by Turner (1969) as aggregation or incorporation (p. 94). While Turner goes on to suggest that this stage is characterised by stability, questions endured for the parents in this study about their experience of transformation. Within that process, however, they identified rituals or events that facilitated the incorporation of a different and new world of being a bereaved parent. Within Theme 3, entitled "Emerging from Liminality", parents described the rituals and events that facilitated their movement towards the boundary of this liminal transformation.

For bereaved parents, the involvement in rituals and events at EOLC within the hospital facilitated parents to commence the integration of the bereavement. Referred to as "meaning making" by Neimeyer (2001) and others (Valentine 2019), this process is critical to parent's bereavement journey as they struggle to make sense of their child's death. These processes or events were undertaken by parents, either because it felt appropriate for themselves, or because they were promoted or parents were facilitated to engage in activities by hospital staff, acting as "spontaneous communitas" for the parents in this situation.

It may be anticipated that the parents' local community, including their extended family would provide them with a more "normative communitas", a community that is "purduring" or continuing to exist for bereaved parents (Turner 1969). The examples provided by parents highlight the challenging nature of the development of normative communitas, as some of the families' natural community continued to connect with them after their bereavement and some did not. Turner (1969) explains this by describing a normative communitas after a liminal experience as built on "grace" rather than "law" (p. 49). While many parents (as outlined above) found the immediate support provided by their communities, an important part of their bereavement experience, many remarked on how difficult it was for their extended families, friends, work colleagues and community in general to find a way to integrate the loss into their everyday contact with these parents.

5.4. Conclusion

In this chapter the experiences of parents during the end of life and death of their child while under the care of an acute children's hospital have been explored. Nine of the children in this study died on site, three were discharged home to die with the support of the palliative care team, one of whom is described by the parent interviewed as having had a sudden and unexpected death. The analysis of these 15 parents' experiences was centred around three themes which crossed the liminal stages of separation, margin or "limin" and aggregation (Braude, 2012). In depth exploration of these themes provide a clear understanding of the experience of a parent whose child died, and the similarities that can be found in that experience, despite differences in the background of the death.

CHAPTER 6: STAFF EXPERIENCE IN CHILDREN'S EOLC: RELATIONSHIP-BASED CARE IN CHALLENGING CIRCUMSTANCES

This, the second of three findings chapters, reports and discusses the findings generated from researching experiences of EOLC from the perspectives of a cross disciplinary cohort of staff comprising of nurses, doctors, HSCPs and social workers. Data was gathered using focus groups at the site hospital (see Table 9 for composition of the focus groups and profiles of the focus group participants). Seven focus groups were held in total and 24 staff participated in the research process.

In the first section, the findings from the experiences of 12 health care professionals (doctors, nurses and HSCPs) will be examined. The challenges of recruitment and facilitating these groups within a very busy acute hospital have been discussed in chapter 4, including the challenges of finding an appropriate time to plan for the group, in addition to the last-minute difficulties with staff availability due to high clinical demand. The second section will present the finding from the focus groups with 12 medical social workers recruited. Again, as reported in Chapter 4, the recruitment of the medical social workers was straightforward, with a higher level of the team volunteering to become involved, fuelled by their desire to gain a greater understanding of the study process for their roles as gatekeepers and family recruiters. It is, however, important to recognise that staff took part in these groups while on active duty within the hospital and, despite the challenges, made time to be involved, due to their commitment to and investment in their work at EOLC.

Throughout the first section, the doctors, nurses and HSCPs will be referred to as "staff". They will be distinguished from the staff group in the second next section which consists of medical social workers who will be referred to throughout as "social workers". Within the analysis, I took the decision to analyse the focus groups with staff and social workers separately for two reasons. Firstly, I was interested to see if the findings from the social work focus groups would be different from findings from the other staff, due to the predominance of psychosocial interventions within social work education and the social workers' experience in providing psychosocial care to families at times of crisis. In addition, I was aware of the low level of published research on the role of social workers in children's EOLC within the literature review. I also believed that the findings from this research could add to the small number of published findings on the social work role in this area and to teaching and education with the social work field.

In the reading of these findings, it should be remembered that, at the time of the deaths of the children involved in this study, palliative care was provided within the hospital from a “Level 2” perspective (Ryan et al 2014, p. 13) meaning that a palliative care approach was provided within the provision of a general medical service, not at a specialist Palliative Care level. All staff (except one) involved in these focus groups carried multiple other duties within their roles and worked in EOLC as a part of a multiplicity of responsibilities.

All of the findings will be examined using the framework of liminality outlined in Chapter 2 and used as a lens to examine parents’ experiences in the previous chapter. Particular emphasis will be placed on the experience of liminality as described by parents in Chapter 5 as it is reflected in the work of the staff teams who care for them. Staff highlighted the uncertain nature of the work, as well as their experience as part of the “spontaneous communitas” (Turner, 1969) that is built around the family. Turner’s (1969) discussion of the concept of “spontaneous communitas” normally refers to the natural grouping of people who surround an individual as they go through the experience of a Rite of Passage (Van Gennep 1903/1960). In this study, the spontaneous grouping of individuals that parents discussed most was the staff within the hospital. Therefore, in this study, this grouping refers to the staff, with the term “spontaneous support system” used. As individuals, the individual staff role of holding particular expert authority would fit within Turner’s (1969) description of being an “instructor”. However, as discussed in Section 6.1.4., this title was modified to reflect the evolving role of staff within EOLC to “guide”.

6.1. Section 1: Analysis of the Findings of Health Care Professionals Focus Groups

In examining the findings from the Health Care Professionals (“staff”) focus groups, I return to the study’s research question as the focus of this section:

“what are the experiences of staff during children’s hospital-based EOLC?”

From the outset, staff recognised this work as different from their everyday responsibilities, and the preciousness of this time with families. One staff member reported how she learned very early in this work the high level of responsibility that is

integral to working with families whose lives have gone into crisis because of their child's illness.

"I guessed what I learned about was how quickly a family's life can flip on a ... on a coin." (Staff010)

Staff were worried and concerned to do their best for children and families at this critical time in their lives. For staff, this was a responsibility that they took very seriously. One doctor described it as "being the person in charge of the child's death". For staff trained in a medical model where cure is the goal, this can be a very challenging position to find themselves in, and in many ways is counterintuitive to their main professional role (Kane and Primomo, 2001).

Staff recognised that time at EOLC was limited, recognising both the chronological and phenomenological concepts of time, and the importance of ensuring that families used the time they had with their child the way that they wished.

"We can't have those boundaries, we can't have those boundaries for them, and we can't go "whatever", [we need] to look at what's important to them as a family and not what we think is important to them. I think that's really important to say to them "this is your time, you decide how it goes." (Staff005)

However, staff recognised the oppositionality that is a feature of liminality. They recognised their own limitations within this situation in that their best professional skills could not change the inevitability of the child's death. At the same time, their experience has shown them they could work alongside the family, and try to facilitate their wishes, and in some ways try to reduce what they described as the "trauma" for these families. One staff member remarked:

"I don't know if being prepared is really possible ye know." (Staff006)

While she was referring to the families involved, there was a strong sense with the focus groups that this belief applied to staff as well. The complexity of this oppositionality for staff working in children's EOLC reflects the findings within the literature review that staff require a high level of competency and skills within their clinical work as well as an ability to be reflexive and emotionally competent in order that they can provide good care to

families (Hain et al., 2012; Hughes et al., 2014; Jones & Weisenfluh, 2003; Ryan et al., 2014).

In a very complex medical setting however, staff acknowledged that, once it is clear that a child will die, the supports that can be provided are more straightforward, in contrast to their usual experience of providing complex and highly technical medical care to a child. Examples of these supports were: sitting with a family or doing simple things like helping with a hair wash, or a bath, or going outside for a walk. They talked about important times when a family would simply ask the staff member to sit with them, for example in the ED while the team were trying to save their child's life, or at the bedside while their child died. They emphasised the importance of recognising these important times for families and ensuring that, as staff members, they worked to provide protected time for the family with their child. One staff member spoke of a mother who recognised the importance of being able to make the move from complex interventions of acute care to the seemingly more straightforward practices of EOLC.

"She was so grateful for a simple thing like that, simple things." (Staff009).

However, as will be explored later, the provision of that "simple" care entails a huge emotional toll, one that staff spoke about at length (Papadatou 2009). The staff firmly believed that they did their best to ensure that the experience for a child and their family is a positive as possible. However, the impact of this work on staff was discussed on numerous occasions, not just from the staff's personal perspective, but from an overall concern about the toll that this work can take on team members as well.

"We're not robots like, this affects us. [...] Yea, we're not just cogs, you wouldn't be in this job if you didn't care, [...] if you care, you get affected ... Em, I've a very like ... thick skin myself but it still stays with you." (Staff010)

This introduction to the findings from the focus groups provides a glimpse into this challenging world for staff who undertake this work of caring for children and their families at EOLC in the busy and demanding environment of an acute children's hospital.

Meta-theme: Implementing End of Life Care while Recognising its Challenges

From the analysis of the staff focus groups, the overall theme "*Implementing End of Life*

Care, while recognising its challenges” reflects staff’s transition from implementing highly technical and complex medical care, into the liminal world of EOLC. The attributes and skills required to do this work successfully are clearly identified and acknowledged by staff as different from those required for their complex medical interventions. This point reflected Goymour et al.’s (2019) finding of staff’s need to actively refocus their interventions when they are working with a child who is dying, so that the child can have a “good and proper death” (Mu et al., 2019). In this research, this recognition by staff of the different type of care they are providing in EOLC resonated with the experience of parents being in an unknown world, in that it is different from the “normal” work – requiring active readjustment on behalf of the staff. The importance of this refocusing is reflected in the findings in the literature review of the long-term repercussions for parents if these relationship with staff do not provide them with a positive experience (Dos Santos et al., 2020, Falkenburg, et al., 2018; Sellers, et al., 2015).

Staff experiences are detailed within the three sub-themes which arose within the analysis, providing details of staff experience within the liminal world of EOLC.

6.1.1 Theme 1: Recognising the Need for End of Life Care

Within the focus groups, staff discussed in detail how they went about implementing EOLC with a child and their family. In addition, they spoke about four other areas of that care namely: staff actions to promote EOLC; family-centred care; cultural aspects of care; and the challenges they experienced.

i. Staff Implementing End of Life Care: Within this sub-theme, staff described their experience of working with parents when the need for EOLC was introduced, creating a spontaneous support structure around the family within the hospital setting. As members of this support structure, staff recognised the challenges for parents living within this complex world. They discussed the difficult transition for parents as they recognise that their child’s health is so compromised that a move to EOLC was required. Staff described this difficult transition as indicative of parents’ resistance to the idea because it meant that they had to face the likelihood that their child would die. In addition, they expressed concern about the high level of complex emotions parents facing these discussions experienced, with phrases like “absolutely out of it” used to describe a parent’s level of confusion and emotion.

With sudden deaths, staff also recognised the importance of providing time for parents to become accustomed to these challenges and difficulties, and to try to find a way to understand their changing world. O'Malley et al. (2014) points to the challenge presented to staff in this situation as they try to develop a compassionate relationship with the family while also recognising their limitations to resolve the medical crisis of the child. Staff in the present study reported that one of the interventions that can be helpful for families is when a child is moved from the ED to ICU for care, even if the final outcome for the child is already known and the interventions medically futile. This nurse describes the psychological benefit for families of this time, so that parents can know all possible medical interventions were provided so their child had the best chance of survival:

“Yea I think a lot of families come and they think that “We’re going to [site hospital], everything is going to be ok” and then everything isn’t ok, but then there is comfort in them knowing that they have tried, everybody has tried everything, that’s a big thing for them. ... So that’s important even if its futile. [...] So sometimes you feel, ye know, if you are the receiving nurse the reality is, “Oh God, this could have been, this journey’s been wasted” but it isn’t, because it makes them feel everything was done for their child.” (Staff007)

Staff described how, for other families where the nature of their child’s illness provided more possibility of having a planned approach, the transition to EOLC was smoother. Staff found it easier to manage the child’s care when there was agreement with parents about the appropriate plan going forward.

For some of those families, parallel planning was implemented. Parallel planning in palliative care is the concept of having a plan to continue active treatment while also planning for a deterioration in health allowing a softer and longer approach to EOLC planning (Gupta et al., 2013; Thompson, 2015). This meant that the team needed to anticipate and plan for the possibility that a child’s health could deteriorate. One doctor reported:

“I find myself probably being one of those people who, if it even crosses my mind that its going to happen in a year’s time, not necessarily imminently, but if I see that this is a child with a life limiting condition and see what the trajectory may be even if I am not sure, I will probably pick up the phone and inform my colleagues here [...] to talk about parallel planning.” (Staff001)

However, as the next quote explains, some staff identified the fact that there is never the perfect time to introduce EOLC, but that the early introduction of the concept allowed parents to begin to understand how seriously ill their child was. This nurse reported:

“It all boils down to communication and knowing when to step in and when to have those conversations. [...] you might think that today is not the right day, but it probably is the right day, because ... the sooner the information is given, the sooner that people can begin to deal with it like it’s, d’ye know.” (Staff005)

For staff then, their role was to become part of the family’s spontaneous support structure by acknowledging and supporting parents to recognise that the more appropriate approach to their child’s care was now to provide comfort at EOLC.

ii. Staff Practices to Promote End of Life Care: This area of work is acknowledged within the extant literature to be fraught with challenges, and rarely uncomplicated (Carnavale, 2007; de Vos et al., 2015). Within the focus groups, staff identified specific practices that they undertook within their work to promote the concepts and philosophy of EOLC. These practices centred on: recognition that the child was dying and acknowledging and prioritising the needs of the child and family at that time; working with other teams and specialities; ensuring that family time with the child was well spent through memory making; and caring for the child and family through the death process. These practices can be seen to facilitate parents in developing ways of coping by becoming familiar with and managing the liminal landscape of their child’s EOLC.

In some situations, discussed by staff, the recognition that a child was dying was an extended process, involving multiple hospitalisations and a progressive introduction of the concept of palliative and EOLC to the parents. In these circumstances, staff felt it was critical to keep parents apprised of their concerns for the child, while at the same time ensuring the child’s comfort was prioritised, as this participant explains:

“it came to the stage where we weren’t sure we could treat any more, and we had already been talking and we were trying to parallel plan, and prioritise comfort.” (Staff003)

In the circumstances of a sudden death, staff described the work of informing families of the seriousness of their child’s condition in a necessarily truncated timeframe. One nurse described the importance of providing markers for parents to help their understanding of

the serious nature of their child's illness. She described the use of witness resuscitation to provide families with visual prompts to begin enabling them to realise that their child will not survive, reflecting Shaw, Ritchie, & Adams's (2011) finding in their literature review that parents overwhelmingly find this procedure difficult but beneficial in understanding that the team tried to do everything for their child. This nurse describes in this next quote how having parents in the room with the team during resuscitation can help parents to understand the process and understand that the team has done all they can for their child:

"I think that's where the bringing them into resus and showing them what you are doing. [...] once they can see it, I think, you can give them a better picture, whereas sitting them in the quiet room or a room like this and saying "we're working as hard as we can, but it's not really working" they'll say "keep trying as hard as you can." (Staff008)

In order to ensure the most appropriate approach was taken to EOLC, staff often consulted with other specialities to support and review the decisions that were being discussed. Here, staff in this research echoed findings by various authors cited in the literature review who outlined the importance of a team successfully working closely together, to clear guidelines with mutual respect for all team members (Chan et al., 2016; Mickan and Rogers, 2005; Turner, 2010). Staff in this research explained how having these other experts become part of the family meeting about future care provided "a counter" to the primary physician, facilitating parents to develop a trust that this was a generalised opinion, not unique to the consultant they knew best. Staff spoke about how the presence and availability of other members of the multidisciplinary team developing trusting relationships with the family, also added to the level of comfort that the team could provide to the family, as this next quote illuminates:

"I think the extended people around the team are so important like the social worker, if they have had time to build up a relationship and if the chaplain is there and has had a relationship with them as well, ye know I think both of those, I think it's the continuity, it's the building of relationship, it's them feeling safe and confident in their environment and minimises their [family] distress." (Staff007)

With children who are hospitalised and die within a short time frame, staff described how they engaged in promoting "memory making" activities for the family, including, where possible, activities that were close to the family's experience, or in keeping with their

usual family activities, and not causing discomfort to the child, reflecting the findings within the published research about the importance of memory-making (Martel & Ives-Baine, 2014; Viridun et al., 2015). Staff described facilitating parents washing their child's hair, bathing their child, going out for a walk in the fresh air, putting a mattress on the floor so that parents could sleep with their child, and completing important religious rituals. This next participant explains how while these are often quiet events, carried out within the ward, that sometimes they spill over and take on a different meaning for families:

“Yea like one of our last babies that died, I swear to God they ended up having a big flipping hooley party in the room! And like it was the right thing to do, they were lovely. [...] And at one stage I was laughing “I nearly came in to tell ye to keep the noise down” like, cause it was, there was singing, now just singing with the kids like, [...] it turned into complete celebration. Totally unexpected like and it was lovely, it was her party and it was the only party she was every going to have.” (Staff005)

For staff, the purpose of these processes was not only to create joint memories, but to provide parents and families the opportunity to “reclaim” their child before he or she died, and allowed staff to try to recreate experiences that parents might have as a family with the child in everyday life.

When it came to the time for the child's death, staff worked hard to ensure that as much as possible, comfort was provided to the child's family. In this next case described in the quote below, meticulous planning and a cessation of the use of mechanical monitoring allowed for a baby to die in her mother's arms with minimal medical intervention:

“And again like it was because we had planned it, [...] and it allowed the girls [nurses] to know that “no, we are not doing obs, we are just doing comfort measures” and the baby can stay where she needs to stay like so and “yes it's ok, if a suction is needed you can suction there on mammy's chest and leave her alone”. So, like that, the plan was really really good cause it gave everyone confidence em ... with it, and that death went as smoothly as deaths can go like [nervous laugh].” (Staff004)

This example together with the other practices described that are undertaken by staff, showed the deep understanding of and commitment to the sense of being part of the

spontaneous support system that surrounded the dying child. It demonstrates how staff use their expertise to undertake practices that they knew would support parents and extended family during EOLC. This sense of active engagement by staff in prioritising family experiences as a central part of the care provided is largely absent within the literature reviewed.

iii. Family-Centred Care: Staff commitment to their role in children's EOLC was supported by the family-centred approach espoused by the site hospital in their care of families. This approach includes the involvement of the child and their family in making decisions about the child's care (Price & Cairns, 2009). This family-centred approach, which staff were familiar with, facilitated the development of the spontaneous support structure that developed around the child and their family at EOLC. Staff spoke about how important it was to recognise and respect parents' wishes, including for example, a clear discussion about the possible location of the child's death. Such staff practice allows for the opportunity to communicate with parents, to enable the most appropriate decision making (Mitchell & Dale, 2015; Zaal-Schuller et al 2016).

In addition, being respectful and inclusive of the possibility of siblings being present and involved during EOLC was an important consideration for staff. While there was no consensus among the staff in this research about a definitive recommendation to include siblings, staff recognised the need to discuss with families whether or not they wanted to have siblings involved, and to facilitate this happening if families felt it was appropriate for their other children as recommended in the extant literature (Brooten & Youngblut, 2017; Gaab, Owens & MacLeod, 2014, Giovanola, 2005). As this member of staff pointed out, it is critical to help families, often in crisis, to think about the future consequences of the decisions whether or not to include other siblings in this process:

"I've said to a few families in that situation in ICU mostly that they can be quite a scary environment to bring a child into and hesitancy in around bringing them in, is to reflect on how they would feel in ten years time about this. And maybe ok that child might only be seven or eight or even a teenager, comes back to them as an adult and says "was I there when they died?" whether he was running around or not ye know, it might mean a lot to them." (Staff001)

Indeed, staff regularly discussed the importance of support persons within the family's extended family or friends, remarking how "family" as defined by the rules of the site hospital were not always the most supportive people within the parent's life. They saw

this in terms of the hospital extending their concept of family to “family of choice” rather than simply family of origin (White 2004). Staff emphasised the importance of making exceptions to visiting rules, if necessary, to include these supportive individuals, as defined by the child’s family, not the hospital rules. In one situation, a nurse spoke of how a parent wanted to have her sister with her, and not grandparents as defined in the hospital policy, and felt it was important to make an exception in order that this parent could have this chosen, supportive family member with her.

“We had a death a couple of years ago and the mum was really close to her sister, now why on earth would anyone think it would be ok for her sister not to be there? I can’t understand that, none whatsoever. So I think it’s really important if they want anyone to be there, they should have them, absolutely. (Staff010)

However, at times, they believed that this approach could be compromised in the delivery of good EOLC, due to the lack of experienced staff to be available to support families, especially outside of ICU and outside of the regular working hours.

As staff have identified, including the needs of all family members, and anticipating their needs into the future when the child will have died, is a critical part of their wish to provide excellent family-based care during the end of their child’s life.

iv. Cultural Aspects of Care: Within the present research, staff identified that the usual practices at EOLC within the liminal space of the hospital needed to change to facilitate individual family’s cultural beliefs and practices. Staff spoke about the extra demands of working with families from different cultures and the need to ensure, in as much as possible, that language and cultural differences were acknowledged and respected. However, the attention to and awareness of this cultural or language difference added another layer of focus, requiring staff to ensure that they imparted information correctly and ensured an empathetic approach to the family.

“Yea, it’s hard to impart your empathy to someone in a different language, isn’t it, do ye know what I mean, like obviously you’ll sit there, but obviously its difficult. You want to be empathetic to them and you want to talk to them about their baby, but its just the language barrier is quite difficult, isn’t it?” (Staff007)

Staff drew attention to the additional complexities of communication with a family who spoke a different language, while at the same time trying to ensure an empathetic approach, so often communicated through talking at the bedside.

In addition, staff were cognisant of the fact that practices around death will be different than the dominant culture in Ireland, reflecting findings in the literature that a family's religious and cultural beliefs may impact on how they perceive EOLC (Brierley et al., 2013; Gray, Szulczewski, Regan, Williams, & Pai, 2014). As staff, therefore, they needed to be aware and respectful of that difference, as this participant explains:

“But even as a bedside nurse you’d do that, ye know ye wash them, you don’t wash others, you ... close their eyes, you don’t close their eyes, the family wash them, ye know you have to be very cognisant of all of that as well, and that has definitely ... eh ... has changed over the last ten or fifteen years.” (Staff008)

As a more extreme example, staff reported that these cultural differences can cause particular difficulties for staff. In one example, a senior nurse described how a couple, from a country in Western Europe, had different expectations in relation to the management of their child's pain, with the parents expecting that heavy sedation would be provided for the child. When this was not in accordance with normal practice at the site hospital, parents became very distressed and fought the staff to change their practice. During a prolonged period of EOLC, this caused a high level of distress for both parents and staff as the next quote illustrates:

“[...] there was a very different cultural understanding about palliative care with those parents as to what we were used to. [...] It was actually just terrible, [...] this poor child, [...] These parents felt that ... every time he moved he should be given something to help sedate him as such, more and more morphine, more morphine even when his movements were not due to distress. And it really became quite contentious around that time.” (Staff006)

In these situations, high level of understanding of the different cultural and religious practices was essential for staff and to deal with what they described as “ethical dilemmas” for themselves raised by these different beliefs.

v. Challenges of End of Life Care: Staff recognised that the complex and turbulent liminal world of EOLC brought challenges that needed to be recognised and

factored into practice. Many of these challenges highlight the difficulties that the lack of clarity at EOLC can bring, be it in communication, lack of planning, or lack of agreement about the best way forward in the care of the child (Davies et al., 2008). As emphasised in the literature review, untimely and difficult communications can deeply affect the parent-staff relationship which can cause difficulties in planning for the child (Hendricks-Ferguson, et al., 2007; Mack et al., 2005; Marsac et al., 2018).

One of the ways that staff reported facilitating good communication was to use unambiguous language when interacting with families, particularly due to the high number of staff members that families encounter. One staff member spoke about “leave no ambiguity, ye know” adding that often having other members of the team to witness those complex medical discussions, allowed them to reiterate that unambiguous and definitive messages to parents:

“So you have different consultants or a nurse, ye know different people from the MDT [multi-disciplinary team], to be there to be say and to be listening to that conversation and to be part of that conversation that “this is how it is for you, we’re really sorry but this is how its going to be”, and to be very definitive about it.” (Staff008)

This need to reinforce the clear message using other staff as witnesses arose regularly through the focus groups, often with reinforcement as to the essential nature of this practice. One staff member reiterated this needed to be “very straight, to be honest”, suggesting that if you didn’t do that then “you’re screwed!” (Staff008). Staff worried about the amount of time and work that is required to ensure that families have understood this difficult message that their child would not survive. Staff perspectives align with research findings that highlighted the difficulties between staff and parents (Archambault-Grenier et al., 2018; Verhagen, 2018). However, their discussion of the role of other staff witnessing conversations as a positive way to facilitate parents’ understanding is not discussed in the literature.

In a further departure from the findings within the literature review, staff felt that some of the challenges in EOLC came from the systems or processes within the hospital. In particular, and as expressed in this next quote, caring at night-time when there was less staff was also a challenge, as was providing appropriate facilities and privacy for parents:

“Ye know ye do your best, ye don’t have rooms, you don’t have quietness, no matter what you’re going to have other children coming, you’re going to have admissions from casualty that are really sick, [...]. Possibly other nurses get pulled away, ye do your best.” (Staff004)

Above all staff spoke of wanting to tailor care to individual families’ needs. They spoke of the importance of not making assumptions and knowing that bespoke care was critical, so that staff do not risk the family undertaking a “physical retreat” by avoiding contact or meetings when staff they are more familiar with are not on duty. The family retreating could seriously affect staff’s ability to provide the care and support that is a central function of the relationships built as part of the spontaneous support structure surrounding the family. In this research, this need to “tailor” a bespoke care package for the family was seen as central to successful EOLC as this staff member explained:

“every family are very different, and I think what each family found helpful, ye know crying with them or not crying with them, that’s not, you have to tailor what’s, you have to try to see what people want [...] and you’ve been with them for a long time and you’ve built up a relationship. But I think you can’t say, some families find some things incredibly important to them and some don’t find that at all.” (Staff007).

Despite all of the challenges, staff clearly identified an innate respect for the child and their family and the unique bond that existed between them (Kearney & Byrne, 2015). In their reports on their work in EOLC, identified earlier as taking place within a busy acute hospital where this was not their primary role (Ryan et al., 2014), staff in this study very much reflected Bloomer, Endacott, Copnell, and O’Connor’s (2016) findings that staff endeavour “to create normality amidst the sadness and grief on the death of a child” (p. 5). In their approach to the care of the child, staff in this research were clear that they need to be respectful and to understand that each family will make different decisions about how they wish EOLC to occur.

6.1.2. Theme 2: Developing Relationship Between Staff and Parent

Throughout all of the interviews, there was a focus on the relationships that staff developed with the people they worked with. This relationship can be understood within Turner’s (1969) concept of “Instructor” who is present within the liminal space, as a more experienced individual to provide guidance and direction to the new person within this

rite of passage, in this incidence, the parent. Staff provided descriptions of this role, with its inherent challenges and difficulties.

In some staff's perception, this role of guiding took place within their professional boundaries, but for others they reported that the professional boundaries were stretched beyond what they were comfortable with. This reflected the inherent complexities that exist for staff in children's EOLC in finding a balance within the work of personal commitment and professional boundaries, an issue that features in the current literature on the impact of EOLC on staff (Papadatou, 2006, Brown & Warr 2007, Payne 2008). The time and effort that is invested in the development of that relationship through constant communication between staff and parents is strongly evident within the findings. The parent-staff relationship therefore needs to be highlighted as the main vehicle for navigation of this liminal space and is significant for both staff and for parents, as was seen in the previous chapter.

In reviewing the extant literature, a key finding arose in relation to the importance of developing a relationship with the dying child and their family (Mack et al., 2005; Marsac et al., 2018; Michelson et al., 2020). In this study, staff reported the importance of developing a relationship with the child and their family over time, often over many years, sometimes all of the child's life. This involved an active process, of getting to know the family in the context of their world outside of the hospital, understanding their reactions to various hospitalisations and interventions, understanding what their hopes were for their child. When it then came to the time for planning EOLC, staff reported that they would then know what was important to the child, even if the child could not speak for themselves because of their medical condition, as they had gotten to know the child and their personality over a long time. One doctor reported;

“cause it was important to her, I would feel that exactly, so that's the difference, if the child had the ability to ask and say what they want.” (Staff001).

Respecting what they anticipated the child would want was important to staff and was a strong influencing factor in their decision making about introducing the concept of EOLC. This knowledge of the child and their family facilitated discussions with parents and families about care decisions going forward. In particular, staff reported that good working relationship can provide a firm basis on which to have conversations around difficult topics with parents:

“I think it has stayed with me for a very long time, when I work with patients with long term illnesses, about how building a good relationship that when the rocky road hits, that that family will feel that they can hear the bad stuff from you, ye know, so I think its about having that good relationship, being honest with them.” (Staff002).

In fact, staff reported that the development of that trusting relationship in the early days of a child’s deteriorating health, allowed parents to renegotiate around their own changing needs, including the possibility to change a previously expressed wish about location of death, reflecting the importance of what Falkenburg et al. (2018) call “connectedness” between staff and families in children’s EOLC.

This development of that good relationship was built on staff’s ability to recognise the individual family context in the move to EOLC. Part of that context was to recognise parent’s emotional reactions at different points in the process and to adjust the pace of information giving or decision-making as needed. Staff reported “picking up cues” from parents that they had had enough information provided. They also reported acting as “interpreter” to revisit information that parents had received in order to promote understanding and to acknowledge their emotions attached to receiving that information. As this HSCP reported, it is a critical part of the work to support families during that time:

“We spend a lot of time with the family, the diary pretty much gets cleared, the bleep gets ignored, and this our priority [...] cause you were there [...] for the good, the bad and the ugly cause that mother will cry on your shoulder and that father will scream and roar on your shoulder, and you’ll take everything that comes with that and like I’ve had days when there’s tears or snot and everything on my shoulder from those parents, and I feel so lucky to provide that, that’s part of my job.” (Staff009)

This understanding of the family extended to understanding the dynamics between parents, and their ability to support each other in this difficult process, as this doctor described as she worked with parents to develop their understanding for the needs for EOLC:

“if I was trying to take a step forward, and one of them wasn’t coming with me, they would bring the other along and it was [...] really impressive.” (Staff003)

Key to developing this working relationship was the staff's ability to recognise and respect parents' wishes in relation to how the care plan for EOLC would take place. For staff, this meant discussion, planning and documentation of the EOLC plan so that all staff on the team could understand parent's wishes. And staff understood that this plan may not be exactly what the health care professionals would expect or agree was the best plan, but they knew that respecting parents' wishes was critical:

“And I think you have to respect parent’s opinion, [...] if we can even though you might think “oh this isn’t the right thing”, you have to give them, this is their child, and they want the best thing for them.” (Staff006)

And staff recognised that these needs were not always static and were happy to change a care plan if that was appropriate for a particular family. They recognised that parents' ability to participate in planning can fluctuate at times, often depending on the complex and fluid emotional processes that parents go through. This came down at times to the language that they used with parents. One staff member citing a couple's dissatisfaction with the use of the word “comfort” in EOLC, arguing that, in their worldview, a child's death could never be comfortable. In other circumstances, staff recognised the need to judge the amount of bedside presence by staff that parents' feel comfortable with, as the child is dying. This discussion by staff reflected the challenges identified within the extant literature of undertaking future care planning with parents, especially when a child's medical future is uncertain (Dussel et al., 2009; Wolfe et al., 2000), emphasising the finding within the literature that there is a lower level of forward planning generally for child with non-malignant diagnoses (McCallum et al., 2000).

Whatever the individual family's needs, the critical nature of maintaining a good working relationship with the family was emphasised by staff, even if that relationship had at times been contentious, as this participant explains:

“But for the family it was that we remained open and honest with them the whole time, and that we had a prior established relationship of openness and honesty in a challenging case ... for sure.” (Staff001)

For more short term relationships, when a child is admitted in an emergency, the building of that relationship needs to happen quite quickly but can be facilitated by the shift patterns that staff work, for example, long nursing shifts which allow for quiet time with the family, or week-long shifts with medical consultants who see the family every day.

This facilitates the information giving to families and the development of a mutual understanding about the status of the child's health and the most appropriate path going forward.

"I think the most helpful thing for a family is if you have built up a relationship with a family before the passing of their child. [...] if somebody has looked after the child ye know end of life scenario can be very planned, it can be planned, I think that families, I feel it's a bit more helpful for families if you been giving them time, and its not just all of a sudden, a non-planned event is much more difficult to deal with then a planned event, so I think planning, a discussion, a collaboration with the family, ask them what they want to do, allowing them to dictate how they want it to go, I think that's what families find really helpful." (Staff007)

Staff identified a number of ways they developed that relationship, including actively working to understand the family, understanding the child's family context, advocating for the child, respecting parent's wishes around care options, and recognising parent's emotions.

However, staff also identified the particular challenges to the development of this relationship binding staff and family together within the liminal space of EOLC, when time is restricted. Staff reported that at these times, they needed to protect themselves from the difficulties of being exposed to such a high level of emotion. This is expanded on in the next theme.

6.1.3. Theme 3: Impact of End of Life Care Work on Staff

As in the literature review, staff in this research spoke extensively about the impact of this work on themselves as professionals and individuals and the toll that working in children's EOLC can take. As staff have identified, a pathway to a "good death" is difficult and challenging (Mu et al., 2019; Remke & Schermer, 2012) with the high emotional toll being well documented (Bateman et al., 2012; Forster & Hafiz, 2015). For staff in this research, three major subthemes arose: the emotional impact of the work; staff suitability for the work; and staff caring for themselves.

*i. **Emotional Impact of the Work:*** The staff reported that the first step was to acknowledge the emotional impact of the work at children's EOLC care.

“I think it’s great to talk about it, to acknowledge it, the effect on staff of dealing with end of life, I think it quite ... not unacknowledged but I think the stress of it is unrecognised, sometime, somewhat.” (Staff006)

Staff acknowledged that the effects can be “profound” and that particular parts of the EOLC can be more stressful than others. They reported, for example, the challenges of EOLC when there is little or no time to get to know the family or plan with them how they would like the time to be spent. Equally staff reported that when they have been caring for a child for a long time and have built up a relationship with that child and that family, their reaction can be stronger - “ye know longer term connection which make it more likely that you have grief and other thoughts about it” (Staff001).

For staff, there were different opinions about the appropriateness of expressing their emotions in front of families, with no clear consensus about what might or might not be appropriate. In general, staff believed that the priority was to protect themselves, and ensure that they didn’t compromise their professional role in front of families, despite the challenges that this presents, as the next quote explains:

“A lot of the other cases are really traumatic cases and you’re you’re meeting families you don’t know, you’ve never met with them before, you’ve no relationship with them, you’re going discussing the death or the possible death of their child, and you’re trying to be ... warm, but you’re trying to protect yourself in it as well and have that barrier built up as well and it’s it’s very difficult, its very very difficult, em.” (Staff007)

For staff, strong emotions were evoked by parts of EOLC that were perceived to cause difficulties for the parents or family. For example, unexpected deaths were reported to be “probably the hardest ...” (Staff005). Staff also reported that having to explain on top of that sudden death that a post-mortem would also be legally required was also very difficult as this staff member explained:

“And I mean, the case, especially when they talk about post mortems, and the parents get very upset and the parents say “why do you need to do that to my child” and there’s angst and there’s ye know there’s anger and there’s frustration, and we get all of that, so it’s not that often that we have that, I suppose, a good experience.” (Staff007)

In other situations where a child had been provided EOLC for an extended period because there have been differences of opinion between staff and parents as to the most appropriate pathway of care, there can be a sense of relief when the child dies and that difficult dynamic doesn't have to continue.

"That's a very different impact on your staff, and also depends on the relationship with the parents, ye know. Sometimes it can be a relief that the child had died and passed away, and that, no longer ... and that those conversations are not ongoing. So ye know there's no sign, again no size fits all because it just depends on the circumstances, ye know." (Staff007)

Staff highlighted this as a particular source of stress, reflected in O'Brien et al.'s (2010) description of the complexities of caring for a child when the medical interventions are no longer of benefit to the child, but parents are not in a position to agreed that these active interventions should stop. Staff in this study reported that, as professionals, they are working to empathise with the parents and understand their perspective that agreeing to EOLC would represent them "giving up" on their child. At the same time, however, staff have to manage their own concerns for the child that the current plan is not the appropriate pathway of care, as it involves multiple invasive interventions that are no longer effective. These situations where their dual responsibilities to the patient and the family came to the fore were particularly distressing and "traumatising" for them as described by this staff member:

"It can go the other way as well, we had a child, a case of a child who did pass away but she had, was in hospital for the first year of her life, and had multiple life threatening episodes which required resuscitation but it was a very, we all felt that it was a ... , and all the professionals involved felt she was never going to survive, but the parents, it took them a full year to come to an acceptance that they, that you wouldn't have full resuscitation in the event of a life threatening episode. [...] That was a huge issue for them and that was very traumatic for all the staff, cause obviously over a year, you build up a very good relationship with them." (Staff006)

And sometimes it is a challenge for staff to figure out which of the competing demands on them is causing the distress or if it is the combination of other pressures in addition to the bereavement that can cause the pressure. They can be working on a busy ward,

with other demands to care for sick children or it can be surges in the demands on the hospital such as the busy winter period.

*“So I can’t pick out whether it’s the bereavement or the whole other winter thing, like the horrendous winter that we’ve had and the stress that people are feeling on a day to day, to shift to shift, to hour to hour basis, cause it is constant.”
(Staff009)*

As articulated in the next quote, staff identified feeling distress because the care plan wasn’t clear among the team, leaving them unsure of the appropriate approach to take with parents

“there was just loads of questions that weren’t answered, like that other little baby died fine, and died in mammy’s arms and everyone comfortin’ and all around, but it just, say the staff outside the door, had a lot of questions and a lot of queries, whether, could we be doing things better? Where, they did everything absolutely fine, the baby was fine, but then when we had our care plan in place, everybody’s reassured that everyone was doing was the right thing to do what they needed to do and then that took stress off staff cause they knew what they were doing and they knew they also had a reference to go back to.” (Staff008)

Staff also recognised the lasting impact of these experiences on them and the impact of relationships built up with the child and the parents. At times though, rather than getting the sense of completeness that comes from caring for a child until they die, staff reported that they felt that completeness didn’t happen when children were transferred to other care facilities, more local to their family home, for their last days of life. For them, it felt like their work was not complete.

“And they were very caring, very nice parents, and then when the decision was made, they felt that the best thing for them was that they go back to her local hospital so that they could have more quality family time, which they did, cause they got her out, they got her out for a walk, probably the only walk of her life, and she passed away two weeks later after that. It was actually quite hard here [...] cause we all had a bond [...] It actually feels like she should have died here.” (Staff006)

ii. Staff Suitability for Work in End of Life Care: Within the focus groups, staff clearly identified staff suitability as a key factor in the management of the emotional impact and stress of working in EOLC, reporting that they felt that not every health care worker was suited to work in this area. This discussion was not reflected in the extant literature reviewed as part of this research. Senior nursing staff in this study identified certain personality traits that they felt were more suited to this work including the ability to be calm, kind, flexible, and resilient, qualities they believe cannot be taught;

“Some people will never be [...] comfortable with it, but there are some people who do it extraordinarily well and its lovely then to put a genuine staff in with them and see then if its appropriate, and that’s a lovely thing to be able to do, because I think I learn by example ye know. I remember a couple of people I worked with and I remember thinking “Oh my God, if I could speak like that!” If I could be as comforting as that to people, like, if I could find that ...! So I think we can teach but mostly by example, it’s not a textbook thing!” (Staff008)

Senior nursing staff reported that they would look for these traits in a nurse before assigning her to work in an end-of- life situation. While reporting that they would not assign a student nurse to this work, staff reported that less experienced staff can also do well, if there is a good match between the staff member and the family.

Other staff confirmed that suitability was important, emphasised the need for flexibility, particularly if staff have the ability to recognise that they need to be flexible in their approach to care in order to meet individual family’s needs.

“But when a child comes in like say for palliative care, ye don’t know what’s going to happen, you just have to slow down the process and stay in the moment, and I think that’s impossible for some, [...] because if this is the end, this has to be the best end it can be cause there’s no going back on it, and you can’t take back time and you’re building memories.” (Staff009)

This extract clearly highlights both the importance that staff place on providing EOLC and the responsibility that they carry to ensure they provide that care in the best way possible. Together with the emotional impact of this type of work, the weight of the responsibility to provide each family with the best experience possible, considering their circumstances, weighed heavy on staff. While none of the staff interviewed talked about burn out, or compassion fatigue as identified in the literature (Larson et al., 2017; Rourke,

2007), staff in this research demonstrated an understanding of the need to care for themselves as professionals as described in the next section.

iii. Staff Caring for Themselves: Within each of the focus groups, as well as recognising the impact of this work on themselves and their other team members, staff spoke of the ways that they try to care for themselves in this work. Within this study, staff discussed many of the coping strategies found in Muskat et al.'s (2019) study, which found multiple coping strategies among staff including professional (compartmentalisation, support from colleagues and formal support from the organisation) and personal (actualizing personal traits and beliefs, personal life boundaries, family and friend support, taking time/maintaining outlets).

Staff in this study clearly identified that, if staff are unaware of the emotional impact of the work, then their ability to recognise that you might need help may be impaired, resulting in long term difficulties for the staff member either within work or at home. Staff talked about the need to create a boundary between their work and their home life, stating that their significant others did not choose to be in this work, and therefore either will not understand it's emotional impact or should not be asked to do so.

“Yeah there’s a bit about that, I think we’re all realising that you can’t ... do everything and it will never work if you do, you have to have some boundaries, em, em ... I think even sometimes, bringing these things home is a challenge, in that, ye know, I find that my family don’t always, it’s an upsetting thing to talk about, it not in their line of work dealing with, or would want to deal with as well, and it’s not that they wouldn’t offer support, but they are often not the best people to offer support.”(Staff003)

Some staff discussed the boundary that they created for themselves between professional life and work life in order to acknowledge the emotional impact of the work, to protect themselves and be available to other families that might find themselves at EOLC. The HSCPs also spoke extensively about the emotional impact of the work, how their work is a “vocation” and they are lucky to do it, but yet it takes quite a toll on them, and that they need to be able to separate their work life from their home life. Staff also commented however, that it does affect their private lives, sometimes being reminded of a child who died outside of work, or needing time to “readjust” from the emotionally laden environment of their work to their “outside” lives. Staff spoke about the emotional impact of the work in all four focus groups.

A number of sources of support available within the site hospital were identified by staff. These included:

- **Team Support:** Staff reported that they received support individually from other team members or from a line manager, or indeed provided individual support to staff in the form of a cup of tea, a quick chat or a more formal meeting if needed. Staff regularly spoke about small gestures, being individually told of a child's death if not on duty, a quick chat in the corridor, being given some space by their manager after the child died.
- **Debriefing:** Staff reported two types of debriefing that took place on a regular basis: "Hot" debriefs which were undertaken with a shift leader as soon as possible after the child dies and before staff return to other duties; and "debriefing" provided by a psychologist either from the Occupational Health Department or brought in from outside of the site.
- **After Action Reflections:** These are structured reviews usually taking place within 2-4 weeks of a child's death inviting all members of the multidisciplinary team to discuss how the death went and reflect on the learning from that experience.

These avenues of support were discussed at length in all interviews with staff, even if the meaning of the types of support was different for different staff members. For some, support was found in their "peer support" network within the department. For others it was being told in an appropriate fashion that the child had died, or a chat over coffee with a peer or manager, or sometimes a formal discussion with a senior member of the team. This discussion fits well with the previous emphasising by staff in this study of the boundary between professional and work life, the challenges of EOLC and the emotional aspects of the work.

In the end, however, staff felt that ensuring they had enough support for themselves in managing the emotional and distressing parts of this work was critical to ensuring that they could continue in this work.

"Yeah put it somewhere, accept that you're sad, accept that it's a very distressing thing [...] accept you may need some support but not necessarily ... ye know that grief you can deal with but then be able to, as I said, em ... it has to have

boundaries, you can't carry it with you, you can't carry it, ye know we all have lives outside of work, you've got your friends, you got your all of life outside of work, we all have other patients who need our care and support, or who will need our care and support." (Staff003)

6.1.4. Discussion

In this review of the findings from the health care professionals (doctors, nurses and health and social care professionals) interviewed in focus groups, a number of findings are important to highlight, in particular that staff also enter a “different world” when caring for a child at EOLC. In parallel to the experience of parents, this is not the normal, everyday work experience that they are used to, but requires different ways of working in order to be respectful of the grave and difficult situation for the patient and their family. As discussed in examining parents’ experience, this experience of liminality brings with it a sense of ambiguity and uncertainty, a sense of living “betwixt and between” (Turner, 1967). Turner elaborates on the complexities of liminality by talking about the experience in terms of “a series of binary oppositions or discriminations” (Turner 1969, p. 106). This description exemplified the context in which staff work underpinned by the following dichotomies: cure/dignified death; high technical skills/ being “present”; complexity/simplicity; using professional skills/using emotional knowledge; feeling skilled/feeling deskilled; work with a low emotional impact/ working with a high emotional impact. Understanding this duality helped staff to make the switch to the skills required for EOLC and to understand their own frustration, at times, at the competing demands of their other work. So EOLC too is a “liminal” world for the staff, outside of their normal expectation of their work.

The staff clearly demonstrated their role within the spontaneous support system that is created around the family within the hospital setting that is a feature of this liminal space. Based on the social relationships that are built up within the physical and emotional spatiality of EOLC (Turner 1969), staff played a vital role in this support structure that is built around the child and family at EOLC in a hospital (Braude, 2012). Adapting a family-centered care approach in a paediatric hospital involves the inclusion of the child (if appropriate and possible) and their family in the decision-making process in relation to how a child’s care is managed (Gill, Pascoe, Monterosso, Young, Burr, Tanner, & Shields, 2014; Price & Cairns, 2009; Smith, Swallow, & Coyne, 2015). This family centered approach, which staff were familiar with, facilitated the development of the spontaneous support system that developed around the child and their family at EOLC.

In the examples included here, staff reflected how important it was to recognise and respect parents' wishes, including for example, a clear discussion about the site for the child's death and planning for death at home if possible. They demonstrated how they worked hard sometimes over years, sometimes over a very short period of time, to get to know the family and to be present to provide expert information and advice, to support the family and to simply be present at the bedside, if that is what the parents' wanted.

For many staff, their role as an "instructor" was an important element of their work. While Turner's (1967) concentrated on the element of authority within the instructor role, in that it can be seen that staff provided an essential element of support through the provision of medical and health care information to parents, there were further elements of care identified by staff in providing guidance to the families through this difficult time. These elements included providing possibilities for families and encouraging them to do things their own way. This expansion of the role for staff when complex medical interventions were no longer appropriate supported the concept of staff as "guides" rather than instructors and was central to this changed use of terminology within this discussion of the research findings, in order to highlight the different approach and skills required to provide the most appropriate care when a child is actively dying.

However, the more negative elements of being an instructor or guide within EOLC are highlighted by staff in relation to the toll that this work can take on them. In some staff's perception, this role of guiding took place within their professional boundaries, but for others they reported that the professional boundaries were stretched beyond what they were comfortable with. This reflected the inherent complexities that exist for staff in children's EOLC in finding a balance within the work of personal commitment and professional boundaries (Papadatou, 2006, Brown & Warr 2007, Payne 2008).

Within this section of the chapter, I have explored the findings from the focus groups carried out with 12 staff members from different professions working in site hospital. The focus groups explored their experience of providing EOLC to a child and their family and provided the opportunity for staff to reflect on that experience. The analysis of the findings provided an overall theme of "Implementing End of Life Care while recognising its challenges". Three sub-themes were discussed: recognising the need for EOLC; developing a relationship between staff and parents; and the impact of EOLC work on staff. Examined from the viewpoint of liminality, the experience of staff was recognised to be one of being a key enabler for families in their understanding of the world of EOLC. However, it needs to be recognised that this places particular demands on staff who are

caring for a child who is dying and their family while also balancing the other responsibilities of their post within the hospital.

6.3. Section 2: Analysis of Focus Groups with Medical Social Workers

The following is an analysis of the focus groups carried out with the medical social work participants. As previously described, 12 medical social workers volunteered to become members of focus groups due to their role as gatekeepers with the families recruited for this study. The medical social workers believed that their own involvement in the study would provide them with a better insight to explain to families what being involved in the research entailed. Three focus groups took place with four medical social workers in each group. The structure of the groups reflected the structure of parent interviews as well as staff focus groups.

Within this section, the discussion centres on the social worker's perception of their role. They clearly identify the complexity and uncertainty that features within the concept of liminality. Their support to the families could be clearly defined as within the spontaneous support system created for the family within the hospital space. However, their role as instructors or guides are somewhat different from the other staff, in that their care is concentrated on the parents and family, reflecting their family focused approach to this work. As these discussions unfold, the details of the complexity of this work are revealed.

In examining the findings from these focus groups, I return to the research questions to structure this section:

“what are the experiences of social workers during children’s hospital-based EOLC?”

From the outset, social workers were very conscious of the enormity of the task that they undertake when working with families at EOLC. One social worker expressed the seriousness of the situation as working with a clear recognition that the family would never be the same after the child died. She described this period as:

“when family are dying”. (StSw012)

Despite extensive years of experience for many of the social workers, they demonstrated the weight of this work by questioning their helpfulness with families who are facing such a daunting experience:

“its such hard work, it really is, and its just not knowing am I really benefitting? Am I really helping? Am I...? ye know it’s difficult, it’s so difficult. I donno, its hard.” (StSW021)

However, within the focus groups they often answered that concern. They talked about the fact that they sometimes overlook the impact on families due to the pressure of ensuring that they get things right for families at this very difficult time. One social worker explained it this way:

“Cause I think sometime we underestimate it, sometimes with families I think “oh I’ve done nothing”. And then actually, some very small things that we do was really powerful for someone.” (StSw019)

However, the humanity and dedication with which they described how they undertook their work was encapsulated in some of the special words or phrases that populated their discussion. For some it was particular things they remembered about the children. For this social worker, it was the constant crying of one of the children she worked with, as she struggled for life: “I’ll never forget her cry, ye know...” (StSw011). For another, it was the encapsulation of the character of this small baby who was only alive for a period of months, and spent all his life in the hospital, whom she remembered affectionately: “the little man”. (StSw015). For others it was the recognition that children and their families could still have precious and special moments, despite the awfulness of their situation. One social worker described the work with her multidisciplinary colleagues to create an environment for the child to die, whereby they had all worked hard to fulfil the parents’ wishes to make physical changes and introduce readings and music while the child was dying to bring comfort to the family. She described them as: “these actually beautiful momentous things”. (StSw012)

For all of the social work participants, being present and witnessing the family’s journey was the essence of their work in children’s EOLC. This social worker summarised her social work role in caring for families at this time:

“I think it was that kinda, just being gentle, being gently present, gently available.”
(StSw011)

Meta-theme: “Enabling Families to Find their Own Path”

This concept of being “*gently present, gently available*” reflects the essence of the overall theme from the analysis of the social work focus groups, which is “Enabling families to find their own path”. The analysis provided a clearer understanding of the complex world of the dying child and the social work role within that world. It highlighted the work of the social workers on site to encourage, support and enable families who enter the difficult and challenging world of their child’s EOLC. This overarching theme encapsulates the work of the social workers in the difficult and challenging emotional space with families who are facing the death of their child in an acute hospital. It further emphasises the social workers’ efforts to work with them to ensure that this experience is as family centred, and as appropriate for each individual family as possible, taking into account their background, previous experiences, and ethnic and cultural beliefs. Social workers worked to empower families by providing information, support and guidance. Social workers identified this time with families from the point at which it was recognised that a child was dying, be that in the emergency department where a child presents as critically ill, or where a move to end of life is negotiated with parents as part of a palliative care approach for children with long term conditions.

As discussed in the literature review, research on the role of social workers in children’s EOLC is limited. The findings from the social work focus groups reflected the broad discussion of this role within the literature that social work training provide social workers with the essential social work skills to support families at this time, particularly as evidenced in this research in the areas of listening and counselling (Jones, 2006a). However, the findings of this research provide a more detailed description of the role that social workers find themselves in, particularly in relation to specifics of the role that they play in supporting parents to navigate this particularly challenging experience. Theme 3 – negotiating competing discourses, demonstrates how social workers negotiate the different influences within children’s EOLC and has some resonance with ethical dilemmas that Csikai (2004) identified for social workers in adult hospices. However, as mentioned above, the social workers in this study identified the key role in their work of bearing witness to the child’s death and to the distress that is caused to families in their passing (Jones, 2006b; Vargas & Ostrander, 2012).

In this study, four major themes were identified which support the social workers' approach to EOLC:

6.2.1. Theme 1: Engaging with Families & Navigating Across Boundaries

Within this theme, social workers identified themselves as working in the space between the medical and nursing staff who were working to medically care for the child and the family, navigating the complex information, procedures and language used within this work. They identified their support role to families in situations and practices where the medical experts were interacting with the family in relation to challenging medical information. They also identified situations where aspects of the medical world were limiting the family's understanding or involvement in their child's care or where communication with the teams was challenging, or where there was no agreement about the appropriate way forward for the child. Social workers often acted as "interpreters" of the dying world for families through interventions within their multidisciplinary teams:

"so em talking to the team about using very simple language and making sure that what was being said was being understood and checking back in with them. Em and I think as well not being forced to make a decision or being given a specific time frame around when end of life needed to happen." (StSw014)

At times, the interventions provided by social workers were complex and difficult. They found themselves in positions between the family and the multidisciplinary team. They raised questions for the team as well as the parents' perspective on their child's quality of life, in order to ensure that a full and rounded discussion takes place about the child and the future medical care, that is in keeping with this family's perspective:

"... well I think some people [in the multidisciplinary team] were very clear what the right thing was. I sometimes wasn't and we talked it through with staff members saying "does she not have a reasonable quality of life?" [...] she wasn't necessarily suffering in between but yet she was never going to have this magical quality of life but her parents were well aware of that [...] So I think, I don't know it was just a very difficult position to be in because you were trying to advocate for the child and the parents. And yet then questioning yourself like, gosh am I doing the right thing here or ... " (StSw018)

For social workers, communication was a major part of this work, clarifying with families and then with multidisciplinary teams about what is possible in relation to the child's care, what might be possible and how a family would like to influence that process, if feasible. A social worker identified the different pace at which medical experts and parents understood the child's medical position and sought to advocate for parents with the team if needed. These situations at times were frustrating for social workers, as the following participants explain:

“the confusion between the message from the consultant at the start, I think that was difficult for mum.” (StSW013)

“as time went on and [child] deteriorated, the wishes of the family differed from maybe what the hospital staff felt was best, in the best interest of the child.” (StSW011)

At times, this meant introducing challenging topics in discussions with families to ensure that, in as much as possible, they understood all of the processes that were taking place, and at times, were prepared by the introduction of topics the family had not anticipated. In one particularly difficult case, this social worker described how she tried to work with a father who found it very hard to face the fact that his child would die and was removing himself from the hospital in order to cope:

“as the time went on and her death was imminent, we just tried to make that clear [...] that time was running out and tried to encourage the mum [...] to ensure that he [dad] didn't have any regrets really but at the same time respecting that this was his coping mechanism as well.” (StSw011)

Social workers believed that this “navigation” supported the family to become familiar with the medical world at EOLC and enabled families to be as involved as possible during the latter days of their child's life.

6.2.2. Theme 2: Mediating End of Life Care

In this area of work, social workers described how they advocated and undertook actions that supported the family during the time their child was dying. They asserted that they worked to ensure that the care, if possible, was provided in the family's best interest.

“because we were able to be ... just clear and confident in the process and explain that to them made that easier for them.” (StSw017)

“no no no no no like ‘this is your chance, you ask any question about your child that you need to ask, this is the time’.” (StSw021)

This involved advocating for the family or ensuring that they anticipated parallel needs of hoping for a recovery, while at the same time having a plan that anticipates how the parents would like things to happen if the child is actively dying. In one of the focus groups, a lengthy discussion took place between focus group members about how they introduce to parents the discussion about their wishes around the circumstances of the child’s death and care immediately after death. The social workers involved concluded that, while difficult, this work was very important, so that both family and staff can then concentrate their time and energy in the present moment with the child while recognising the uncertainty of the situation. This interaction between the focus group members provides an example of this thinking:

StSw014: “and then they can park it and be there. And then to know we can do this.

StSw015: Mmm [in agreement], we’ve a bit of plan.

StSw016: So its all about just trying to pick the right moments, isn’t it? To get, to share that information with them.

StSw014: Well the most, well my experience certainly is that most families they will have that conversation. Ye know it fair to say ... I don’t know if you guys have the same?

Group: Yeah Yeah

StSw014: But that they actually do want to, it’s like the elephant in the room.”

The social workers were clear about the different elements of their role at EOLC, for example the need for advocacy; ensuring, where possible, that the pace at which families would manage information was respected; ensuring that the child’s EOLC was personalised; and that the parents self-determination was acknowledged and facilitated. This acknowledgement of the individual nature of this experience for families extended even to anticipating their needs into bereavement and the significance of the social worker as a witness to that child’s short life:

“... like their baby didn’t meet an awful lot of people, it’s like [site hospital] was their life, and like you are saying, we knew, I knew their boy, and we knew the faces he pulled and we laughed about those things and d’ye know to have that with somebody.” (StSW015)

In addition, social workers highlighted differences within families that needed to be facilitated and respected within the interactions between hospital staff and the family:

“Well I think it’s very important to know what their culture is around bereavement. I think to explore that with them from the get go if a child is dying or actively dying or possibly going to die. Ye know if that ... ye know to find out how, how they do things in their own country.” (StSw016)

“its huge for them to be able to say “look, this is God he is taking her”, ye know, its their way of trying to reason it out and it helped them so much and in that sense its good that their belief is so strong.” (StSW021)

Social workers were able to recognise that this mediation of hospital processes benefitted families and provided them with the support that was needed during this difficult time:

“it did work, ye know the family did get as much a possible a positive experience for his end of life care which was good considering how difficult things had been.” (StSw010)

6.2.3. Theme 3: Negotiating Competing Discourses

Within this dying world, the social worker identified the various, and often competing, discourses that were influencing the experience of the hospital team and the family working together. In this context, the definition provided by Fook (2016) was employed referring to “ways in which we make meaning of and construct our world through the language we use (verbal and non-verbal) to communicate about it” (p. 86). The discourses of: “a good death”; family systems; medical discourses; palliative care discourse; social work discourses; medicolegal discourse; parents’ rights; siblings rights were all highlighted in the focus groups with social workers. In addition, the vulnerability of those families within those competing discourses was highlighted:

“Ye know, sometimes people are, a lot most of the time, people are very vulnerable in a hospital setting if they have a child in here [...] so I think it’s just you could take nothing for granted.” (StSw016)

Social workers described how they regularly found themselves in role in balancing all of these discourses within the frequently narrow timeframe of EOLC. They highlighted how communications, often involving the imparting of highly complex medical information, can be misinterpreted by parents who are not used to this environment in a way that was not intended by the personnel involved. The social workers added that they need to engage in supplemental supportive discussions with parents to help them work through the dilemmas that they face as a result, as demonstrated in this extract:

“And I just think the reason I am thinking about this family for this study is the the struggle that dad talked about around the idea of letting him go. And ... dad really struggled with... however he interpreted the the turning off machines and stuff, he kind of interpreted that it was going to be his decision as to when that was going to happen.” (StSW015)

At times, the nature of these discussions brought ethical challenges for the team as they try to balance the needs of the parents and the needs of the dying child:

“I just think it got to a very ... difficult point to know what was right or was there a right answer here at all and who was going to ultimately make a good decision ye know. “ (StSw018)

They particularly highlighted the legal parameters that surround child death, and the procedures that parents have no choice in, following the death of their child:

“And that they are still that child’s parents, and that they are still ye know up until that moment that that child had died, they have done everything for them, made all the decisions and that at that point when the child died the decisions that have to be made about their child, there is a legal process, but that’s still their child.” (StSW20)

In particular, social workers highlighted the difficult demands of these legal requirements, in particular, organ retention following post-mortem examination:

“there’s no nice way of putting it but you are trying to be as gentle and you’re trying to say and you prepared them and say “look this is not easy” but you are preparing them.” (StSW21)

Despite the complex and completing discourses negotiated by the social workers, their commitment to the families involved was always clear:

“I think it was obviously it was just to facilitate the family as much as possible.” (StSw010)

6.2.4. Theme 4: Enabling Preferences to Minimize Regrets

The final theme identified the social workers use of their expert knowledge to introduce and undertake family appropriate supports during that time because of their understanding of the impact of the end of life experience on the future grieving process for family members. They spoke about the opportunities that were provided to families to avail of the support provided by social workers and the importance of having the time with family before the child died to discuss the family’s preferences, as this social worker explained:

“And that space again was amazing but [...] if we didn’t, if we weren’t able to facilitate that [...] it] would have just been extremely negative and affected the memory of, for them of what was happening.” (StSw012)

Support was often identified as the family having quiet time away from medical meetings and decision making just to be with their child:

“I think they’re they’re little spaces and little opportunities sometimes depending on how sick the child is ye know [...] to try to have those things is nice and it just give the family space to tune out from making the kinda making decisions and ye know end of life care and rescus and all that kind of stuff but just to have some enjoyment.” (StSW018).

However, the social workers also identified situations where the nature of the death was such that the important “spaces” were not available for parents:

“you possibly go from a very well child to an accident to whatever and then suddenly the parents are being kept away and it’s obviously a legal requirement that they can’t see the body but I think its very distressing in their grief and the trauma of that, that sort of loss.” (StSw018)

The social workers identified actions that they took to support parents during the end of life process in order to minimise the impact of such complications by providing support at the time of meeting the family and afterwards.

“Ye know and an’ asking those parents “do you need a support person with you at these meetings?” They are very, can be very intimidating meetings to go to knowing that you are probably going to get the worst news of your life.” (StSw016)

Because of their role in providing bereavement support too, social workers were able to use the relationship built with parents and their knowledge of the end of life journey to support parents in their bereavement:

“I think the support afterwards it was really helping mum navigate through what her role would be now.” (StSw013)

But the social worker’s commitment and understanding of the possible impact long term of the experience of EOLC on parents was clear:

“You can’t have those conversations at a bedside they will come back to haunt you and we are then trying to work with these parents who are stuck in their grief because of a conversation that happened over the bedside that didn’t go well.” (StSw016)

This research provides a clearer understanding of the complex world of the dying child and the social work role within that world. It highlights the position of social workers to support and enable families to find their own way to manage and approach the very difficult experience of losing their child. Their approach is specific and individual to each family

“...ye know often parents say ‘I’m sure you see this all the time’. It’s like well, we don’t see this specific thing all the time, so this is new to you because it’s your

family and really make them feel ye know this isn't just ... 'and Monday's going to roll around again and we are all going to kick over again'." (StSw012)

This approach of providing a bespoke response to each family at EOLC fits the values and beliefs of the social work profession (Jones 2006b) evidencing the key role of social workers in children's EOLC.

6.3. Discussion

Within the analysis of the social workers' focus groups, social workers again highlighted the complexity and confusion of the liminal world of EOLC. They highlighted the difficulties and challenges as they perceived them for parents. Further, social worker saw themselves clearly as part of the spontaneous support system that guided and supported the family during this time. Social workers highlighted the difficulties and challenges of this position, particularly when the parents or medical/nursing teams were not in agreement on the approach to the care of the child. They highlighted the competing discourses at play within the world of EOLC, and their work in negotiating across those discourses. Finally, social workers spoke about a new and key element of their work in which they enabled choices for parents in this process with the specific purpose of reducing the regrets that parents may have around this time. The very important processes in enabling parents to find their own path through this most difficult time has led to the development of a new approach to EOLC within this research which will be discussed in depth in the next chapter.

6.4. Conclusion

This chapter outlined the findings from the analysis of the focus groups with staff and social workers. This analysis highlighted the mirroring by staff of some of the sense of "betwixt and between" that parents experience in the liminal world of EOLC. For staff this meant a moving away from the everyday work, ensuring that they took time to be with families during what they highlighted was a profoundly difficult time. The toll that this specialist work can take was highlighted as well as the challenges and rewards of providing such care within an acute hospital setting.

CHAPTER 7: SCAFFOLDING FOR MEANINGFUL FAMILY EXPERIENCES IN CHILDREN'S END OF LIFE CARE

In the previous two chapters, the findings from analysis of the data emanating from interviews with parents and staff were explored. Within each of these chapters, the experiences of children's EOLC were seen through the anthropological lens of Rite of Passage and Liminality, which convey parents' experiences within a complex, challenging and changing world as their child dies and during the period of their early bereavement. Many of the difficulties and challenges, articulated by both parents and staff, were found to have resonances within the extant literature. Parents in this study reflected the high burden of care during this time, (Bjork et al., 2016; Contro & Scofield, 2012; Melvin & Lukeman 2000; Monterosso et al., 2007) and spoke about the high level of emotion they experienced (Midson & Carter, 2012; Steel, 2005). Parents in this study also emphasised the need for honest and frequent communication (Butler et al., 2015; Hendrix-Ferguson & Haase, 2019; Meert et al., 2009; Suttle et al., 2012) especially when in communication with the medical teams and trying to make decisions about their child's future care (Cacciatore et al., 2019; Hendrix-Ferguson, 2007). In addition, they spoke about their hesitancy to adopt a "Do Not Resuscitate" approach and spoke about the complexities of these communications with the staff involved (Currie et al., 2016b; Marsac et al., 2018; Xafis et al., 2016). Staff in this study also spoke about the necessity and complexities of communication at EOLC, reflecting the extant literature in this area (Beckstand et al 2010, Bogetz et al., 2019; Davies et al., 2008, Mack et al., 2005; Marsac et al., 2018; Michelson et al., 2020). In addition, staff reported the importance of developing a good relationship with families at this time (Kongnetiman et al., 2008).

This third and final findings chapter discusses how, taking a narrative approach, alternative stories that describe other possibilities within children's EOLC have been located within the analysis of the research. These alternative stories are then structured into a "Map of Narrative Practice in Children's End of Life Care" bringing together the totality of experiences reported in this research to create a new approach to the provision of psychosocial care within children's EOLC.

Moving away from research texts can be a difficult but critical step within the research process to complete the task of the inquiry which is to bring forward the meaning within the interview texts (Clandinin & Connolly 2000). Through the use of a narrative approach, and examining the findings using a reflexive thematic analysis, this research explored

the “borderlands” of methodologies, acknowledging the “tensions” that can exist in such exploration which can provide, according to Clandinin & Rosiek (2007) “constantly proliferating counter narratives” which bring forth new ideas and discussions (p. 60). This chapter, then, explores those tensions inviting questions and suggesting possibilities. This process embodies the practice of being a “bricoleur” within the research process (Denzin & Lincoln, 2002), actively stitching, editing and slicing together ideas from the research to create a unity of thinking within the research process (Shaw and Holland, 2014).

7.1. Using Concepts from Narrative Practice to “rescue” Key Findings

In returning to the chosen hermeneutic approach to this research, I questioned whether the fullness of the meaning of parents’ and staff experiences had been expressed, suggested by Ricoeur (1991) as an essential part of any narrative inquiry. In particular, the exploration of the world of EOLC through the anthropological concept of liminality reflected Ricoeur’s (1984) concept of chronological time, a process that parents experienced as having a distinct beginning of entering into the liminal world, the second phase of “being” in transition, and the third phase of beginning the process of emerging from liminality. However, parents also told stories reflecting the experience of phenomenological time (Ricoeur, 1984) as they reported important experiences in their deep connection with their child during this liminal period. These stories were first described as events that involved “having a lovely time” during the EOLC of the child at home, a concept that appeared out of keeping with the challenge and confusion characteristic of the liminal experience. In particular, families who had brought their child home from the hospital shortly before their deaths told stories of seemingly ordinary events like going blackberry picking with the dying child or bringing them for “a little walk around the village” in a manner that suggested that these stories now held great meaning for them in the current context of their bereavement. Because a narrative approach invited the inquirer to listen to all stories within the text, I wondered if these were what Czarniawska (2004) referred to as “legitimate stories” within the context of the parents’ experiences of their child’s EOLC, as they are not the usual stories that are described within this field. In reviewing my notes taken after each of the interviews with parents, I realised that there were stories in each of the interviews that described precious time with their child, often identified by parents as bringing comfort to them now in their bereavement. These extracts had also been coded as “having a lovely time” because of the notes I had made about these stories being told with pride and joy, and, even though

parents often cried when telling the stories, they frequently told them with a smile. I believed that when parents told these stories they connected with the love and pride that they felt about their children. These were usually stories not attached to medical or nursing care, but to ordinary parental or family events that occurred with the child as they died. They were about touching or holding, about singing songs, or reading out good wishes they had written for their child before they died. They were about surviving siblings coming to spend time or arranging family pictures around the bed so that the child could know the family was near. Most interviews contained those stories, even the one situation where the child died in the ED, as described in Section 7.1.3. of this chapter.

I came to understand that these stories providing access to what Ricoeur refers to as the “vouloir dire” or “intending to mean” of the research (Moran, 2002, p. 5). This “vouloir dire” highlights “which narratives are absent, discouraged, contested, or rejected” (Jirek, 2017, p. 184) within the collection of dominant themes within the research. These alternative stories encompassed in the research can be brought to the fore to “generate knowledge that should inform our research, teaching, and practice” (Jirek 2017, p. 184), a process referred to in terms of narrative practice as “rescuing” (Lainson, 2020). This process of rescuing is described by Denborough (2011) as “an act of recovery or preservation from loss” (p. xv) in order to identify and “thicken out” smaller and less dominant stories to open up other possibilities. Adopting a narrative approach has facilitated the viewing of this time in a family’s life from a different perspective than is documented in the current literature, allowing for a deeper understanding of this “betwixt and between” world for the parents. It also foregrounds the nuanced approach that needs to be adopted by staff as they create the essential spontaneous support structure around the family and undertake their roles as guides to the family during this time as discussed in Chapter 6. Such exploration facilitates the viewing of narrative inquiry as a “wonder, a research puzzle” that allows the inquirer to interweave their own experience of the research within the narrative approach to the examination of the phenomenon under study (Clandinin & Connolly 2000, p.128). It was my own experience as a researcher of noticing those stories in each of the interview that allowed the rescuing of these alternative stories. I wondered why parents has chosen to speak about these powerful and comforting events within an overall story that is dominated by tragedy and loss.

In order to contextualise this discussion, I return to the social constructionist perspective on death discussed in Chapter 2, where the argument was made that the social world that individuals experience around the time of a bereavement can influence their

management of the bereavement (Neimeyer et al 2014, Payne, 2009). Support for this perspective can be found in the literature review in relation to grieving parents (Tan et al., 2012). Detailed exploration of the findings from the present research provided illustrations of experiences that nurtured parental autonomy. These experiences, facilitated by staff, allowed parents to reclaim their role as parents of the dying child within the medicalised setting of the hospital. These experiences involved spending time with their dying child and being with their child during and after their death. The examples set out below are illustrations of how subordinated stories were found outside of the dominant themes that parents have told in their interviews. The exploration of these subordinated stories has allowed for the development of an approach that encompasses ideas from the broader narrative therapy field, in particular from narrative therapeutic practice. The highlighting of these practices has supported the development of a framework for children's EOLC in a hospital that promotes resilience and growth within the experience of loss (Keegan, 2011) and exploits the opportunity for the possibility of post traumatic growth (Cadell, Hemsworth, Smit Quosai, Steele, Davies, Liben, S., . . . Siden, 2014). The research findings, therefore, will serve, not just to provide a deeper understanding of family and staff experiences in this context, but to suggest ways that practice can "create stories of agency" and build a practice approach that "builds on stories of strength that engender hope" for all involved (Hedtke, 2014, p. 4). The family and staff stories examined in this research are central to understanding the experience of preparedness for a child's death and to examine how an "intentional state" (White, 2007; Hedtke, 2014) can be promoted. Such an intentional state can result in a better outcome from their bereavement (Nielson, Neergaard, Jensen, Bro, & Guldin, 2016), an issue we now know is so critical to parents' further physical and mental wellbeing, and even their mortality rate (Hunt et al., 2006; Li et al., 2003; Li et al., 2005; October et al., 2018). As Neimeyer suggests

"Like a novel that loses a central character in the middle chapters, the life story disrupted by loss must be . . . rewritten, to find a new strand of continuity that bridges the past with the future in an intelligible fashion." (Neimeyer, 2001, p. 263)

The explorations of these subordinated stories are contained in the next section of this chapter and will be examined using concepts from the narrative school of practice allowing this particular lens to have practical application within this very challenging area of work. The significance of these stories of opportunities offered and taken was so suffused with meaning they became part of the wider narrative of the family, with parents

returning to these stories as a source of comfort and hope. This pointed to the appropriateness of a narrative practice frame and use of key narrative approaches to integrate co-construction of opportunities for family time as part of children's EOLC. From these practices, I will use the concept of "externalising conversations" to explore alternative understanding about problems or concerns by "objectifying the problem" (White, 2007, p. 9) highlighting the process of "rescuing the said from the saying of it" (Newman 2008). The concept of "Re-authoring Conversations" will be used to explore how the creation of different and new conversations can allow both parents and staff to find empowering interactions within this very difficult world of EOLC. In addition, discussion of "Definitional Ceremonies" during and after death will be highlighted as helpful elements in parents' reclamation of their role as parents, a process found to be so much part of their management of EOLC. The concept of "Remembering Conversations" will be used to demonstrate how these conversations between parents and staff can honour and respect the child who has died and facilitate the process of parents creating meaning around their child's death, an essential element in the bereavement process.

7.1.1. Externalising Conversations

As seen in the literature review, communication within EOLC is a critical component of good parent/staff interactions and builds a sense of trust (Cacciatore et al., 2019; Hendrix-Ferguson & Haase 2019; Hinds et al., 2012; Midson & Carter, 2010). However, the research around communication is dominated by the requirement to share medical information at key points in the child's journey: imparting bad news; updating parents with full information about their child's condition and making decisions about the care future appropriate care pathway.

In examining parent's stories to identify "unique outcomes", stories were identified that brought with them the possibility of a sense of agency for parents. These communications were identified by parents or staff as places where alternative possibilities were explored, and other possible practices or actions identified that were comforting to parents. This experience reflects Neimeyer's (2001) contention of the need to create "a new strand of continuity" allowing the past (i.e., parent's love of their child) to become a bridge into their future bereavement journey.

One example of this is the work by staff to respect the parenting role, even if this needed

to be in a limited way because of the circumstances. Being a good parent to their child has been found to be one of the key ways that parents “emotionally survive the dying and death of their child” (Hinds et al., 2012, p. 916). Within the parent interviews, one parent described it this way:

“And what I really found great eh was that they encouraged us to lie up on the bed. That was the biggest thing for me [...]. And like we did jump at the chance at that point and I think we all got value out of that, the girls and us. So that would be something in that scenario to encourage that I would say was really ye know important ye know.”(Par001)

Because staff recognised the importance of allowing parents to have physical proximity to their son, despite the child being in an ICU bed attached to life sustaining machines, staff saw beyond the problems of the dying child, encouraged parents to reclaim their role as parents even within this alien environment of complex medicine. Through this narrative practice, staff can “unpack” the problem story and “make visible information or perspectives that are neglected through the problem story filter” focusing on strategies that will allow the parent to “escape” the problem saturated narrative and “survive the event” (Beaudoin, 2005, p. 33). Through their actions of creating an alternative possibility for these parents, “‘thickening’ of the alternative storylines” of their experience of EOLC (Moxley-Haegart, 2015, p. 59), this parent was not only able to report the helpfulness of this action, but was in a position to suggest that it be encouraged within the hospital at EOLC.

7.1.2. Reauthoring Conversations

The purpose of re-authoring stories is to develop opportunities to create new conversations that provide a different perspective, or a new viewpoint, particularly from a subordinated perspective, to come to the fore (White 2007). In the parents’ experiences described in this research, some examples of these new perspectives or new conversations arose, and provided parents with a new, and more acceptable perspective on their child’s situation. One example occurred in an interview with a mother whose son was born with a life-limiting condition. She described lengthy, complex and emotionally demanding conversations with numerous consultants in the process of trying to decide whether or not her son’s life expectancy might benefit from major surgery. During those discussions, she remarked that there had been conflict between herself and the consultants involved. The mother reporting that she felt they

were questioning her decision to go ahead with the surgery, which she described as “firing these like what I felt were judgemental questions at me” which she found very distressing. Later in the interview however, she described a postscript to this story, which occurred just before her son was discharge home to die. She encountered one of the consultants she had had the disagreement with coming to visit her child:

“...actually I caught her popping down to see [baby] a few days later, the weekend later and I just like I walked straight into her and she just said, “I’m just coming to see your little baby”, and I was like “yea” and she came in and I said come on in and she said “look isn’t he so gorgeous” she was like “Just enjoy this time” [...] like you just felt like she just cared [...] she just wanted to come down [...] because she cared.” (Par005)

This re-authored conversation with the consultant provided this mother with the message that the doctors did care about her child and his story, even if it was about going home to die. This was demonstrated by taking the time to come and visit and have this conversation about how “gorgeous” he was and his achievement in being able to feed, and inviting his mother to “just enjoy this time” even though it was the time while her child was dying. This opportunity for a re-authoring conversation, which now included the subordinated story that the doctor did care about her child, allowed this mother to have a different message about the importance of her child’s life. The mother’s inclusion of this postscript to the story at a later point in the interview, demonstrated its importance for her and its influence on her later recounting of her story of “enjoying” her time at home with her son before he died a few weeks later.

In applying these concepts of “externalising” and “reauthoring” conversations to the Map being created, the terminology of “*reassuring/enabling conversations*” will be used to provide more clear labels for these possible interventions.

7.1.3. Definitional Ceremony

The practice of definitional ceremony comes from anthropological studies examining how individual or group practices facilitate sense making of their key life experiences (Myerhoff, 1984). It refers to the rituals that people undertake, often around key life events, like death, to honour the dead and commence the process of making meaning of their bereavement (Hedtke & Winslade, 2005, Swartz 2009). These rituals are not spoken about in children’s EOLC literature, and yet as is evident from this study, are very

important to parents. These rituals can be undertaking tasks of personal care, telling the staff stories of the child when they were well, or may be very specific, often spontaneous, rituals that parents undertake, particularly around saying goodbye to their child.

In the stories parents told in describing the death of their child, informal definitional ceremonies were regularly described. For one family, this happened at the entrance to the lift, as their son was taken to theatre to die in a controlled way so that his organs could be harvested. At this point in the interview, they described this ritualising of the timing of him going to theatre to die and to donate his organs. They had informed the extended family and their friends outside of the hospital of the time that this was happening, so that they too could be part of this process, highlighting the importance for them of community support even if it was not physically present. Alerting their family network to this significant moment allowed them all to focus on their goodbyes together. They described below how they had spontaneously created a ceremonial goodbye to their son at the entrance to the lift outside of ICU, witnessed by staff who would take him to theatre:

“Par008: We said our goodbyes there

Par007: At the lift

*Par008: At the lift, and then it was just the lift closed and We
kinda said*

*Par007: You [laughs] you were actually, you were so funny, I was
bawling [crying profusely] and you said “don’t let the last
time [child] see’s you be crying and I had to say “goodbye
now [child’s name], good luck!” [crying] [...] Yea [crying] ...
yep [silence].”*

This exchange represents a very important moment for these parents in their saying goodbye to their son. The iteration of the end of the story by Par007 who said “yea” then paused to cry, and then reconfirming the end of the story “yep” again, which lead to a silence during the interview in which all of us in the room reflected on the meaningfulness of the telling of this story. In my research notes written immediately after this interview, I highlighted this interaction between parents as one that, despite the high level of emotions contained within it, brought some comfort to parents, as signified by mother’s

laugh as she remembered her husband's encouragement for the child's last memory to be of them being brave in their goodbye. The defining of this moment allowed parents to remember their child's courage and generosity in his death, and in turn their own courage in making that decision, allowing these values of courage and generosity to become the dominant story of his death, rather than its tragedy. The witnessing of this goodbye by staff who were caring for the child as he went to theatre, and again by myself as researcher, allows for the "thickening out" of this story of courage, providing parents with another opportunity to tell their "re-authored" story of their son's death.

Another story of definitional ceremony was told by a father whose daughter was rushed to the hospital following a tragic accident at home. The father spoke a number of times within the interview of the very strong attachment that he had for his daughter and saw it as his duty to care for her and mind her. A strongly religious family, he spoke about how, despite her very young age, his daughter and himself had planned for a well-known religious ritual known as "First Holy Communion". Culturally, for this father, this ritual marked the full entry of his daughter into their faith. And so, when he arrived at the hospital and was told his daughter was dead, he became very concerned that his daughter had not yet received her "First Holy Communion". He describes how this very important process was facilitated for him by the chaplain in the hospital Mortuary where he first saw his daughter after she died:

"So back to the hospital, the only memory I have after, this is I remember [name of child] being in a room [...] with a haze of fog literally just around her face, only around her face, now I know her body was there and there was people, I couldn't tell you what else was in the room or whatever [...] I don't actually remember her face, but it was her face and I remember I asked one eh there was a little nun or I have her name at home, who was there at the time, eh "can you get communion please?" and I wanted to give [child] her First Communion, cause I knew she was gone and she was going to God and I know now that that thing was still in her mouth but I didn't see that in her mouth, and they gave me a bare little taste of it to put insides of her lip at the time, but they done that for me and that just meant the world to me that I actually gave, cause she didn't get to make her Communion, and I actually gave, gave [child] her a piece like of the Body of Christ inside her mouth and em It sounds stupid or whatever, but that was mine, what I wanted to do." (Par012).

Providing the possibility for this parent to give Holy Communion to his daughter, helped him to fulfil what was, for himself and his daughter, a very important rite of passage within her life, brought him comfort within this terrible situation where she had gone from being perfectly well and playing in the garden of their home earlier that day to being dead. The ceremony of him giving her communion allowed him to see her as his child, and fulfil one of their dearest wishes together, before he had to face the full impact of her death. This ritual continued to bring him great comfort even a number of years after his daughter had died. The chaplain's decision to facilitate what was a highly unusual situation within a religious context for such a young child to undertake their First Holy Communion demonstrated her understanding of the importance of this ritual for this father, and the importance of "breaking the rules" in order to facilitate such a wish, rather than assuming it was not possible. In addition, her witnessing of this ritual, as the hospital chaplain, provided an opportunity for this father to have a story of agency, within the chaotic and traumatic hours after her sudden death.

Within the Map being created, "definitional ceremonies" will be referred to as "*definitional rituals*" providing terminology that will resonate within the EOLC context.

7.1.4. Remembering Conversations

According to White (2007) Remembering Conversations encourage individuals to examine what it has meant to them to have had their loved one in their lives, and to continue to allow their connection with those significant figures who have died to influence their lives. White (1988) defined this concept as "Saying Hello Again" [sic] to reclaim and reincorporate aspects of the dead person's influence on the mourner into their ongoing perspective on life, rather than the more dominant thinking of letting go of a loved one who has died. Hedtke (2020) highlights in particular the importance of parents having the opportunity to talk about their child in order to promote opportunities for meaning making around the death. This enables connection with the meaning that that child's life has had, to be sustained within the parent's life going forward.

Going back to the hospital to have a post-death meeting with the team who cared for the child has been identified in the literature review as a positive option for parents (October et al., 2018). As highlighted within this research, a number of parents and staff have found this to be a very helpful process in clarifying and revisiting questions or issues that has arisen during the child's EOLC. In addition, parents identified that this meeting can also provide an opportunity to remember the child, and to hear messages about the

importance of their role as parents in the process of the child's death. But the process of inviting and negotiating such a meeting and providing such an opportunity to remember is complex. In this example, a mother talks about the process she went through before being ready for such a meeting.

"And I remember [outreach nurse] and [social worker] came out to see me at home and that before Christmas and I remember saying that "I need to go back in there and have this talk" and [social worker] wrote to me maybe the February after Christmas and he said ye know whenever you're ready but it was months before I was ready. Em ... it's not that long ago since I've come in [...] and [consultant paediatrician] said like if you ever have any more questions, just get in touch, she says we're always here and we will answer if we can. So it's good to know ... that that's there if something does pop up in my brain some of the days." (Par011)

The meeting allowed her to put away her concerns that she or the staff could have done something differently and her understanding of her child's death was clear. Later in interview, this mother identified another benefit of the meeting as the medical consultant took the opportunity to speak about how important her parenting has been for the child's quality of life in that he remained at home for so much of his illness.

"And even [consultant paediatrician] like she even acknowledged that at the meeting and she was like "people in hospital think so highly of you cause ye just done everything and it was partly down to you that he spent, that he didn't have to keep coming into hospital cause he was like so well used to doing things at home like the suction and the nebulizers, to keep him well"." (Par011)

And yet, this opportunity might have been missed, if the various staff members had not contacted her after the child's death and provided messages of their openness to having these conversations, no matter how long it took for mother to be ready for them. Even further into the interview mother said about the idea of the meeting:

"... especially with me, it's something I would have put to the back of my mind and in my own time, I would have fretted over it not knowing where to have go with it, where ye have little, little reminders coming at ye every so often which is good. " (Par011)

This sequence demonstrates how, even with a clear invitation to return to the hospital, the process of bereaved parents being able to come in to do this is complicated and requires regular reaching out to parents to encourage them to think about if they are ready. In this example, the benefits of a parent not only getting answers to her questions about her child's death, but also getting to hear from the hospital staff how her dedication and commitment to her son's care had provided him with a better quality of life, is highlighted. This conversation has allowed her to reclaim that role and know that she had been a good parent – a very important element for a parent managing the death of their child as discussed earlier (Hain et al., 2012).

In this section, I have reviewed the less dominant stories told by parents and staff of experiences of EOLC that are suggestive of the use of externalising conversations, re-authoring conversations, definitional ceremony and remembering conversations within EOLC. In exploring the less dominant findings within the study I have returned to Ricoeur's (1991) idea that interpretation should allow the expression of the experience to "become itself", to be seen "in all its fullness" (p. 39). As demonstrated within this section, these practices allowed parents to find alternative stories of agency within their experience of EOLC. They are therefore integral to the proposed "Map of Narrative Practice at End of Life Care" (Figure 2). With the adaptation and integration of these concepts as part of psychosocial care provided to parents and families within EOLC, the possibility of bringing forth the normally subordinated stories of agency and possibility are promoted as an integral part of the care provided to families.

7.2. Introducing a "Map of Narrative Practice in Children's End-of-Life Care"

In order to draw together the key findings from this research and the concepts from narrative practice that can be seen to facilitate the creation of alternative stories within children's EOLC, a "Map of Narrative Practice in Children's End of Life Care" ("Map") (Figure 2) has been created to guide work in this area. The Map encompasses the multiple levels in which children's EOLC is located and in which, according to Bronfenbrenner's ecological model, the parents learn and develop (Darling, 2007; Neal & Neal, 2013). This ecosystem comprises: a) the *micro* or immediate level where the family is situated, in this research this is the ward, the PICU or the ED; b) the *meso* level which is the context of the hospital; and c) the *macro* level which is the community context in which the death occurs.

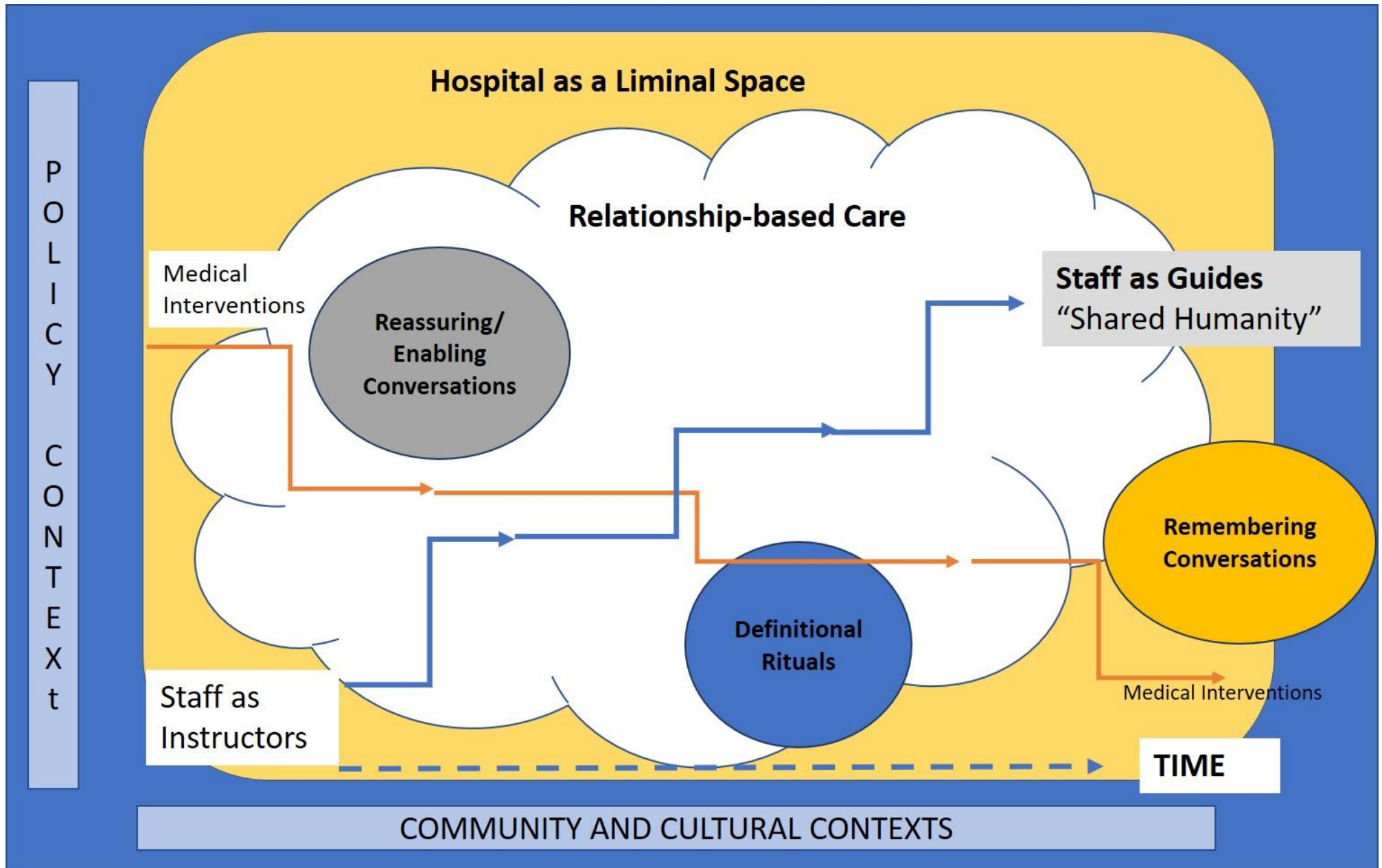


Figure 2: Map of Narrative Practice in Children's End of Life Care

In describing and explaining this “Map of Narrative Practice in Children’s End of Life Care”, the three levels within the Map will be described in detail, drawing connections and possibilities from the different levels of experience for families within children’s EOLC. In order to continue the examination of the key findings from the research, I will start with a discussion of the micro level, move on to a discussion of the meso level and finish with a discussion of the macro level, connecting the research findings with the context of children EOLC in Ireland as discussed in Chapter 1.

7.2.1. Micro Level – “Relationship based care”

As detailed in the previous discussion, the exploration of parents’ EOLC experience using the anthropological concept of liminality has provided a deeper understanding of the confusing and complex world that parents experience at this time. As we have seen, their struggle to enter the world of EOLC, leaving behind their known and assumptive world commences the process of them gaining an understanding of very serious nature of their child’s ill-health. As they journey through this process, the trusting relationships built up with staff allow parents to face the possibility that their child will die. The lack of these relationships has also been seen to lead to a lack of clarity and acceptance by parents that their child will die. Key element of parent’s ability to move towards the emergence from liminality was seen to be their critical experiences of spending time with their child, mainly undertaking ordinary parenting tasks but also sharing some special family events. Their continued connection to the hospital in the period after their child’s death was also critical for parents to provide the opportunity to revisit their experience, have their questions answered and gain support in the early days of their bereavement process, as they faced the world without their child.

Through an exploration of the staff experiences in EOLC, in particular the work of the social work team in “Enabling families to find their own paths” and the exploration of less dominant parent experiences, key findings around the role of staff within EOLC emerged. These findings centre around the recognition of the liminal process for parents, and the importance of the relationship that is developed between parents and staff. Following a presentation of these findings to the Expert Advisory Group attached to this project, the bereaved parents on the group particularly identified with the sentiment expressed by the research participants of their child being treated like an individual, reiterating the importance of experiencing a human connection with the staff who cared for them. This feedback reinforced the importance of the “Relationship based care” concept within the Map.

This area of the Map has a number of key features that, taken together, can allow staff to provide the type of care that parents in this research found most helpful during this most difficult experience:

i. Staff Moving from being “Instructors” to being “Guides”: As discussed earlier, a key concept within liminality is the presence of “instructors” who provide direction to the “neophyte” who is undergoing the ritual journey (Turner, 1967). As seen in the discussion of the findings from this research, staff can offer an extended role within EOLC, moving from the expert and directive role of “instructor” to “guide”, who scaffold conversations such as those that enable and reassure parents, particularly in providing some respite from the high level of distress that parents can experience during this time. This can allow for the inclusion of stories that are not saturated by the dominant stories of powerlessness in the face of the child’s death and allow possibilities for agency and hope within children’s EOLC. The inclusion of these scaffolded conversations would be more aligned to the concept of being a “guide”, providing parents with possible new ways of storying their situation (Chase, 2012) opening up possibilities and alternatives for parents and families with the liminal world of EOLC. Within the Map, the increased use of a relationship approach to care is signposted by the thick blue line which moves from the bottom left-hand side of the Map to the top right-hand side, over time. The increase in this type of care is mirrored by the decrease in the provision of expert and authoritative medical expertise and interventions, as these are no longer required, as it is recognised that the child’s life cannot be saved.

In addition to individual actions by staff members, the interdisciplinary team caring for a child and their family can then provide care using Turner’s (1967) concept of “spontaneous communitas”. Within this project, however, this term has been changed to “spontaneous support structure” to emphasise Turner’s (1967) contention that the major function of this communitas is to provide support based on social relationships during the rite of passage.

ii. Undertaking “Reassuring/Enabling Conversations: Within this proposed Map, staff undertake “collaborative conversations” with families (Hedtke, 2014) through externalising or reauthoring conversations. Within this structure, these conversations are referred to as “Reassuring/Enabling Conversations” in order to suggest a clear and more transparent direction for these encounters. The creation of these conversations can allow for the time to identify and address some of the confusion and complexities parents are experiencing as described earlier while they live “betwixt

and between” worlds. These encounters also introduce a “human” approach to care, recognising that while staff can no longer use much of their expert medical training, they can provide valuable care and support that is vital to the family’s experience of their child’s death.

iii. *Facilitating and Witnessing Definitional Rituals:* These practices would also facilitate or prompt simple and family appropriate “definitional ceremonies” referred to in the Map as definitional rituals. These rituals allow a “thickening out” the meaning of significant moments for parents as they are witnessed by staff, offering for an additional frame for their child’s death. An example of this is the family’s story of courage recounted by the couple in the previous story who were able to describe their son’s death as characterised by courage because he was an organ donor and their own courage in being able to make that decision. In addition, it opens up the possibility of “preferred outcomes” for families as they create public displays of their love for their child and their distress at their death (Hedtke, 2014).

iv. *Creating Opportunities for Remembering Conversations:* In this Map, staff functioning as guides continue to be present through the child’s death and into the early part of the parent’s bereavement. By providing continuing contact and inviting parents to attend the hospital to have a meeting to review and discuss the circumstances of the child’s death, these conversations facilitate parents remembering and, as needed, co-constructing the story of their child’s death with the staff. In this research, parents reported that bereavement follow up in the form of supportive phone calls, home visits, individual counselling or parent group work, added to the possibilities of creating remembering conversations, providing further opportunity for the continuing love of their child to be witnessed and confirmed through a wider audience.

7.2.2 Messo Level – the Hospital as a Liminal Space

As discussed in Chapter 5, the hospital serves as the physical space in which parents experienced liminality during their child’s EOLC. Spatiality is a central concept to both a narrative inquiry (Clandinin & Connolly, 2000) and to the experience of liminality in which the transitional-being undergoes this experience both physically and psychologically (Braude, 2012; Thomassen, 2012). In this discussion of the findings from this study, parents found particular meaning in different parts of the hospital, be it the distress or comfort of a move to PICU, the trauma of ED, or the familiarity and comfort of a ward. For most of the parents in this study, the hospital was the last place they saw their child

alive and the first place they held their child after they died. Within this space too, parents were provided with a “spontaneous support system”. The group of staff who provided care to them during their experience of EOLC guiding them within this confusing and demanding “betwixt and between” world. Within the literature too, hospitals are recognised as places where life is given or taken (Jordan et al., 2015), as a place of sanctuary within the distress of life changing experiences (McKechnie et al., 2010) and the place where new identities are forged (Long et al., 2008). It represents the transition, from the old and known life, to a place where a new sense of being is commenced.

For staff, too, providing EOLC within the space of the hospital presents many challenges as was discussed in Chapter 6. Their normal focus on cure needs to change to the less familiar goal of a comfortable death. In addition, staff have to address the prevailing belief that the most appropriate place for a child to die is at home, when in fact almost half of children’s deaths in Ireland and internationally take place in a hospital. The hospital too, for staff, harbours the personal and professional challenges posed by physical and emotional demands of EOLC. Yet it is also the source of comfort and learning, as demonstrated by their discussion of formal and informal supports, debriefing and After Action Reflections, so that staff can move forward in their preparedness and learning in order to provide a quality service to the next family entering EOLC.

7.2.3. Macro Level – Policy, Community and Cultural Context of Children’s Palliative Care

Within this research, a key part of parents’ journey in EOLC was found to be the opportunity to return to the hospital to meet with the staff who have cared for their child, to revisit the story of their child’s EOLC, in order to ask questions and understand what they have experienced. In addition, they discussed the importance of continued contact with the hospital through supportive phone calls, home visits, and the bereavement support programme.

Within the discussion by parents of their experience of EOLC, their final discussion as they began to emerge from Liminality is described in the present study as “Community response after death”. While parents found that the community were very supportive to them in the immediate aftermath of the death, a number of parents remarked how the community of their extended family friends, and neighbours seemed to be unable to understand the need for ongoing support, particularly in talking about their child who had died.

In addition, both parents and staff identified the impact of the family's community and cultural contexts, with their origins in a family's national identity, cultural and faith system. The impact of these belief systems on parent management of and staff's care within EOLC was identified within the research, in addition to the need for each family to be seen within their own context and provided with supports in a way that fits their belief system.

The creation of this Map of Narrative Practice within Children's End of Life Care emanated from research findings from the examination of hospital-based children's deaths. The Map encompasses possibilities of new relationship-based practice that is based on staff moving away from their medical "expertise" to develop a relationship based on shared human connection around a child dying – encapsulated in the idea expressed by one parent that all of society loses out when a child dies, not just the parent. By including the liminal space of the hospital and the wider community influence on children's EOLC, this map makes the connection between individual family and staff experiences and the wider influences that impact and affect the possibilities of providing an excellent level of children's EOLC. The purpose of this Map, then, is to provide an alternative narrative about children's EOLC, one that encompasses a sense of hope and courage and a refocusing on what is possible within children's EOLC, not what is impossible. The liminal model of EOLC set out in the narrative Map is also relevant when a child dies outside a hospital environment. A hospice or the child's home could also be understood as a liminal space, and therefore an environment in which the practices contained within the Map could be used.

It is my belief that such an opportunity to support bereaved families to find meaning exists within children's hospitals. With a core element of grieving being to "reconstruct a world of meaning that has been challenged by the loss" (Neimeyer, 2016, p.2), then health care professionals at EOLC are in a positive position to support parents in commencing that process through recognition of the possibility of resilience and growth within experiences of death (Keegan, 2011) and of potential for post traumatic growth (Cadell et al., 2014). Through the gathering of the "narratives" of parents' experiences, we can "understand better" (Ricoeur, 1984) the family's experience of the death of child. In addition, being involved with research can be beneficial to bereaved parents (Currie et al., 2016a; Dyregrov, 2004, Steele, Siden, Cadell, Davies, Andrews, Feichtinger, & Singh, 2014; Tan et al., 2012). Consequently, staff at paediatric hospitals can adopt a post-modern approach to the care of dying children in order to expand the possibilities of supporting parents during EOLC of their child (Kane & Primomo, 2001; Papadatou et

al., 2011). The team can support family members in the process of “preparedness” for their child’s death resulting in better bereavement outcomes (Nielson et al 2016), allowing families to develop an “intentional state” (Hedtke, 2014; White, 2007) within the narrative of their bereavement, rather than a distressed resistance to facing the reality of their child’s death.

7.3. Conclusion

In this chapter, I have identified numerous similarities in the findings of the literature review and the findings of this research that reaffirm the importance of communication, the difficult processes within children’s EOLC, particularly the decision to stop active treatment. In addition, the framing of this EOLC experience within the anthropological concept of rites of passage and liminality have provided key findings. Within the further exploration of these findings, unique outcomes were located, allowing for other stories of situations which enabled parents’ sense of agency and encouraged the development of resilience. Using concepts from narrative practice, a Map of Narrative Practice within Children’s End of Life Care was created to highlight how these practices, when “rescued”, allow the possibility of different collaborative conversations between parents and staff with a view to an experience more in keeping with what families would want for themselves in their family and socio-cultural contexts.

The Map of Narrative Practice within Children’s End of Life Care brings a new focus to the use of externalising and re-authoring conversations, in order to provide parents with the possibility of different perspectives, expanding what is possible within the situation of EOLC. In developing the role of the staff member as a guide to scaffold the introduction of these possibilities, the use of these narrative concepts can provide parents and families with alternative practices and perspectives within their liminal journey of EOLC. The capacity to develop and hold stories of agency and empowerment within their journey are reinforced by the practise of Definitional Ceremony and Remembering conversations providing an opportunity for sense-making of their bereavement (Hyvarien, 2008). They also provide the possibility for the guides to act as outsider witnesses (White, 2007) providing acknowledgement to the family’s bereavement and the story of their child’s death (Moore et al., 2015). These practices also allow the stories of agency to be reinforced, with the possibility of disrupting stories of despair about the loss (Hedtke, 2014). In addition, the findings of the present study indicate that these practices have the potential to reduce the psychological pain that individuals go through

in traumatic situations (Moxley Haegart, 2015). In this way, the use of these practices opens up the potential for a bereavement journey that has the possibility of being less complicated. This may lessen the long-term impact on parents' emotional and physical well-being or even open up the potential of post-traumatic growth, reinforcing the possibility that the stories families tell about their EOLC can "affect how they live their lives" (Chase, 2012, p. 57).

Within the last three chapters, I have explored the findings from the parent and staff interviews undertaken for the purpose of gaining a deeper understanding of the experience of children EOLC. Within the exploration of these experiences, the concept of death as a Rite of Passage and a liminality experience were applied from the field of anthropology, providing a clearer appreciation of the challenges and complexities of that experience for parents. These concepts also facilitated the re-examination of the changed role of staff, as active treatment of a child is stopped, and they move away from their highly technical practices and interventions, to be present with and witness this most difficult of experiences for families. In this third chapter, I have explored some unique experiences for families, facilitated by staff that provide continuing comfort to them in their bereavement. Through the use of concepts from narrative practice, a Map of Narrative Practice in Children's End of Life Care has been created to explain these unique outcomes for parents, and provide a scaffold that the interdisciplinary team can adapt to support the creation of these empowering experiences for families at this time.

In the next chapter, the experience of undertaking this research, and the findings therein will be drawn together, summarising the conclusions that can be drawn from the undertaking of this study.

CHAPTER 8: DISCUSSION AND CONCLUSION

This final chapter affords an overview of this study which set out to explore the experiences of parents during the EOLC of their child in a hospital setting and of the staff who care for them. This field of study encompasses a complex and challenging experience for both families and staff who occupy the “liminal” terrain of the “betwixt and between” world of children’s EOLC (Turner, 1967). For parents, theirs is one of the most complex bereavement experiences due to the unique and deep connection between parents and child (Kearney & Byrne, 2011). Witnessing the death of their child brings devastation and complex emotions of despair and vulnerability (Kane and Primomo, 2001; Meert, et al., 2009). For staff too, this is a complex and demanding area of work.

8.1. Introduction: Reviewing Parent and Staff Experiences in Children’s EOLC

The death of a child is a life-altering experience for families (Price & Jones, 2015; Tan et al., 2012) destroying their previously held beliefs about the world (Darlington et al., 2018), requiring all family members to adjust to the difficult reality of this bereavement (Mehta et al., 2008). Both parents and surviving siblings can experience physical and mental health difficulties after this shattering experience that can affect their long-term well-being (Fletcher, Mailick, Song, & Wolfe, 2013; Harper et al., 2011; Lannen, et al., 2008; Rostila, Saarela, & Kawachi, 2017; Wijngaards-de Meij et al., 2005). While some evidence of post traumatic growth is suggested within the extant literature (Albuquerque et al., 2018; Butler et al., 2018; Waugh et al., 2018), for all families, life has changed.

Parents’ experiences, issues and concerns reported in this research reflected findings from the examination of the extant literature in this field. For parents, the similarities between the literature review and the findings of this research centre around the needs of parents at this time, rather than their experience of ‘being’ within the liminal space of EOLC. In particular, parents in this research discussed the high emotional and physical cost of providing care to their child as they died as reflected in a number of studies (Bjork et al., 2016; Contro & Scofield (2012); Melvin & Lukeman, 2000; Monterosso et al., 2007). The need for honest and frequent communication¹⁸ was highlighted by parents in this research as vital to the process of understanding their child’s medical condition,

¹⁸Butler et al., 2015; Hendrix-Ferguson & Haase, 2019; Meert et al., 2009; Monterosso et al., 2007; Petersen, 2020; Short & Thienprayoon, 2018; Suttle et al., 2012; Xafis, 2016

facilitating them to begin the process of coping with the inevitability of their child's death. Parents also highlighted the need for good communication especially when receiving information to enable them to make decisions about their child's treatment (Cacciatore et al., 2019; Hendrix-Ferguson, 2007). In addition, the accounts by parents in this study describing their reluctance to engage with early discussions around "Do Not Resuscitate" orders because of their concern about giving up on their child, is reflective of the barriers to good communication and the challenges in decision making identified in a number of studies (Currie et al., 2016b; Marscac et al., 2018; Xafis, 2016). Parents in this study also shared concerns about their child suffering as identified in the literature (Melin-Johansson et al., 2014, Zimmerman et al., 2016).

Reflecting the extant literature, parents in this study highlighted the need to remain close to their child and honour that relationship (Darlington, 2018; Meert et al., 2009,) through the parenting tasks they highlighted repeatedly, undertaken with the support of health care staff (Aschenbrenner et al., 2012; Butler et al., 2018). In addition, parents in this study acknowledged the importance of various ways of remembering their child that has connection with the hospital, including how they said goodbye (Wijngaards-de Meij et al., 2008), having opportunities for memory-making (Currie et al., 2016b; Meert et al., 2009) and returning to the hospital for post-bereavement meetings (Meert et al., 2009; Snaman et al., 2017).

For staff too, this work is at the margins of their experience in healthcare, working to provide a dignified death for a child, when their usual professional goal is the child's recovery (Kane & Primomo, 2001). With a more usual focus on cure (Forster & Hafiz, 2015), the death of a child can be seen within medical settings as a failure, as the team did not save the child's life, and were unable to fulfil the parents' wishes for their child's recovery (Midson & Carter, 2010; Morgan, 2009). Work in this area is complex requiring a high skills levels (Jassal & Sims, 2006; Payne, 2008), as staff strive to provide care for the dying child and comfort to their family (Sellers et al., 2015).

Within this research, staff highlighted the ways in which they used good communication to facilitate challenging conversations such the introduction of EOLC. Reflecting findings in the literature review, they spoke about the importance of good communication on a regular basis with parents in a manner that is clear and honest (Mack et al., 2005; Marscac et al., 2018; Michelson et al., 2020; Price & Cairns, 2009). Staff emphasised the

importance of including parents in each step of the process of decision making¹⁹. Within this study, staff also recognised the complexities that are inherent in this work (Davies et al 2008, Beckstrand et al 2010, Bogetz et al 2019). These included the development of good relationships with parents often over extended periods of time (Kongnetiman et al., 2008; Mack et al., 2005; Price & Cairns, 2009; Falkenburg et al., 2018; Dos Santos et al., 2020). The development of good relationships can help to deal with difficulties especially in relation to different opinions about future care (Dryden-Palmer et al., 2018; Jones et al., 2008, Kongnetiman et al., 2008, Wierner et al., 2013).

Staff in this research echoed the challenges raised in the literature about undertaking this type of work (Bateman et al., 2012; Dryden-Palmer et al., 2018; McConnell et al., 2016; Muskat et al., 2020) including the personal impact of this work (Brown & Warr, 2007, Papadatou, 2006, Morgan, 2009; Larson et al., 2017). They acknowledged the work-based activities that helped to manage the demands of the work including both informal supports through a “chat” with a colleague or coffee with a senior member of staff, or more formal supports through hospital organised debriefing, or opportunities for reflecting on learning (McConnell et al., 2016; Riotte et al., 2018; Rourke, 2007; Rushton et al., 2006).

8.2. Overview of the Research

This study was undertaken during a time of transition within the field of children’s health in Ireland. With the amalgamation of the current paediatric hospitals in Dublin, and the development of a “National Model of Care for Paediatric and Neonatal Healthcare Services” in Ireland (Nicholson et al., 2017), children’s healthcare going forward in Ireland will be provided through a “hub and spoke” model centred on a new hospital in Dublin, which is now expected to open in 2024. With the international recognition that children continue to die in hospitals (Bluebond-Langner et al., 2013), and the expectation that the majority of child deaths in Ireland will continue to be hospital based (NPMR, n.d.), the new CHI hospital will provide care for children and families in a majority of child deaths in Ireland annually. This study was in part prompted by these major developments in children’s healthcare in Ireland and my participation in the on-going planning process for the hospital over the past number of years. The study aimed to understand the experiences of EOLC from the perspectives of parents and staff and to bring their voices

¹⁹ Beckstrand et al., 2010; Bogetz et al., 2019; Devies et al., 2008; Inghelbrecht et al., 2009; Lotz et al., 2015; Pritchard at al., 2009; Zaal-Schuller et al., 2016

forward to inform EOLC planning for the new CHI hospital. As a result, the key research questions were set out at the commencement of this study were

1. What are the experiences of parents and staff during children's hospital-based End of Life Care?; and
2. What lessons can be learned for future service development?

A narrative framework was adopted for the study on the basis of its potential to integrate the purpose, approach and execution of the study (Clandinin & Connelly, 2000). It also aligned with the social constructionist perspective that is integral to this study, espousing the view that there is no single reality or truth and that individuals will construct their reality based on their context (Lincoln et al., 2011). A social constructionist approach in EOLC contextualizes the end of life and death of a child within the social world, recognising that death is experienced by the bereaved within a social milieu, and their bereavement journey needs to be understood within that context (Neimeyer et al., 2014). In adopting such a perspective, the "work" of the bereaved to adjust to the world without their loved one and to find meaning in that loss, is understood not as a singular internal psychological journey for that individual, but a process that all those in contact with the bereaved person will influence, including the staff caring for a family at a child's EOLC (Hedtke 2020; Neimeyer et al., 2014). Concepts from the field of social anthropology including "rites of passage" (Van Gennep 1903/1960) and "liminality" (Turner, 1967) were introduced to understand and contextualize the "stories" that were gathered from research participants, moving beyond an understanding of the experience of EOLC of a child as an individualised, psychological experience. Theories of Liminality provided a lens to understand the "betwixt and between" world of hospital-based EOLC occupied by parents and the staff who care for them, as their children went through one of life's most profound rites of passage.

A strong ethical framework was created to ensure that participants were "held safely" within the research process and that their narratives are foregrounded in the study. 15 parents and 24 staff members participated in the research. Parents were interviewed individually or with their partner, resulting in 12 interviews, either in their own home or at the research site. 7 focus groups were held with participating staff at the research site. A two part narrative interview approach was used for all interviews (Jovchelovitch &

Bauer, 2000), with a single key question at the beginning of the interview, inviting interviewees to speak in an uninterrupted fashion about the parts of their experience that are of significance for them (Missel & Birkelund, 2011). In the second part of the interview, the researcher posed questions in order to explain or clarify issues raised by the interviewee in the first part of the interview (Flick, 2009). This research was originally designed to include well siblings, and it was disappointing not to be able to include them in the study due to recruitment issues (Akard et al., 2014).

The analysis of the data took place sequentially, firstly examining all of the data using Braun & Clarke's (2006; 2019) "Reflexive Thematic Analysis". The lens of Liminality was then used to contextualize and theorise emerging findings from the Thematic Analysis. Three major themes emerged from the parent interviews: 1) Entering the liminal space of End of Life Care; 2) "Being" in Transition; and 3) Emerging from Liminality. The analysis of the staff interview was completed in two separate groups of: a) staff (doctors, nurses and representatives from physiotherapy, occupational therapy, play therapy and chaplaincy); and b) social workers. This analysis resulted in two meta-themes of "Implementing End of Life Care while recognising its challenges" and "Enabling families to find their own path" respectively. A narrative reading of the parents' stories then took place to reveal the significance of moments in time with their children during EOLC. The deep meaning of these stories for parents and the comfort that the stories continued to provide to them in their bereavement were highlighted. The stories were then analysed using concepts from narrative practice, including Ricoeur's (1971) concept of "vouloir dire" or wish to say, to "rescue unique outcomes" (Newman, 2008) within the experience of EOLC. These narrative practices were then brought forward to create a "Map of Narrative Practice in Children's End of Life Care" which may be used by the interdisciplinary team to explain and promote the key processes in the psychosocial care of families at EOLC.

Having reviewed parent and staff experiences in children's EOLC, this chapter moves to provide an overview of the research. The key findings of the study firstly in relation to the liminal nature of parents' experience will be presented. I will then move on to discuss the centrality of relationship-based care in the context of children's EOLC and finally examining how meaningful and long-lasting family experiences can be supported during EOLC. The implications for interdisciplinary practice in EOLC will be considered. Finally, the limitations of the study are considered and the chapter ends with concluding comments followed by an epilogue and reflection.

8.3. Parent's Experience of EOLC: Entering and Emerging from a Liminal World

In reflecting on the findings from this research and examining areas not reflected within the literature review, it became clear that the fullness of experience of parents, particularly as represented in Theme 2 of the findings – “Being” in Liminality, was not described in the extant literature. This theme from the findings with the parent participants conveys their experience of turmoil within the transition from being a parent of a child who may be unwell but is alive, to a parent who needs to recognise that their child is coming towards the end of their life. This experience is described by Wels et al. (2011) as being neither the person they were before this experience but not yet the person they will become, reflecting the concept of being in that threshold place of liminality. In this research, parents went through this middle phase of liminality by recognising the unknown future of their child, developing trusting relationships with the staff and coping strategies through the development of an incremental understanding that their child would die, recognising various cues in their environment until they had reached the point of being able to articulate this situation of their child's impending death to others. While some aspects of this experience are reflected in Butler et al.'s (2018) research with bereaved parents, the comprehensive picture of this transitional process as provided by parents in the present research is not generally reflected within the literature.

Van Gennep's (1903/1960) concept of the parent as neophyte or novice within the liminal experience helps us to understand the depth and complexity of the experience for parents. It describes the disconnection that parents go through from their known and familiar world, into the liminal space of a hospital where they have to learn to communicate and make decisions about their child, and come to terms with the news that their child is going to die. Parents vividly described the sense of being a novice with feelings of confusion and heightened emotions, at times needing to take non-verbal clues from their environment to try to understand the situation in which they found themselves. For parents, the complexity of receiving this news, while at the same time holding onto the parental responsibility of 'not giving up on your child' was strongly voiced by parents, emphasising the deep and visceral connection between parent and child. Parents spoke about their need to be physically and emotionally connected to their child during this time, reconnecting with their familiar role as a parent.

The exploration of the concepts of space and time within the liminal world of children's EOLC brought other dimensions into focus within this experience. In viewing the hospital as a safe space in which to undertake the complex and confusing experience of EOLC, parents in this research provided evidence of the acceptability of a child's death taking place within a hospital, where parents have the support and comfort of expert "Instructors" (Turner 1967) who are present to support the family but also to provide the reassurance that everything was done to save the child's life. Examining the role of staff through Turner's (1967) concept of "spontaneous communitas" added to the possible way in which we can understand how parents are supported through the liminal experience of EOLC in a hospital.

In addition, parents' frequent references to and explanation of the concept of time within that liminal space provides a deeper understanding of their experience and need for sufficient time within each stage of EOLC. Using Ricoeur's (1984) concepts of time as chronological or phenomenological in nature, allowed for the exploration of parents' experiences from a different perspective. For some parents having chronological time with their child, despite the seriousness of the child's condition, was essential in being able to begin to come to terms with the fact that they would die, particularly in those cases that included sudden deaths after an acute illness or accident. Repeatedly in these cases, parents provided lengthy stories of this time, and how important it was to them to try to adjust to the new and terrifying idea that they would have to face a world without their child. Key memories of time with their child doing simple things like talking to them, combing their hair, or telling staff stories of their child's life are a feature of parents' recollections of this chronological time, memories that bring comfort to them. In contrast to that, a number of parents spoke of times when there was a clash of perceptions between themselves and staff, when staff assumed, judging by the concept of chronological time, that parents had had sufficient time to understand and come to terms with the life-threatening nature of their child's illness. Parents reported that they did not believe they had had sufficient time, from a phenomenological perspective, to accept that possibility, resulting in them believing that they had not been appropriately prepared for the death of their child. The benefit of such examination identified how the perception and experience of time can add to the complexity of communication and decision making at EOLC, particularly if the health care professionals fail to account for the concept of the phenomenon of time, rather than simply its chronology.

8.4. Relationship-Based Care in a Liminal Context

Within the findings of the research, the need to redefine the role of staff within EOLC emerged. Staff were initially identified with the more traditional concept of “Instructors” (Turner 1967), who are seen as authority figures and experts within this liminal world. However, the findings from interviews with staff suggested the possibility of a different approach, one in which the aspect of authority and medical expertise became less important as EOLC evolves and the focus moves to facilitating parents to find their way within the liminal world. Staff emphasised both the centrality of developing relationships with families and the personal impact of this work on themselves. The four main themes emerging within the analysis of the social work focus groups further suggest the emphasis be placed on a biopsychosocial approach to enabling families find their own path through EOLC:

- a) *engagement with families* to support them in understanding complex medical information about their child, and the complex hospital systems whereby their child may be cared for by multiple medical teams, specialities and sub-specialities;
- b) *mediating* or advocating for families so that their wishes are articulated and foregrounded where possible;
- c) *negotiating competing discourses* where conversations occur about the meaning of a good death, active treatment or palliative care, medicolegal considerations and the challenges of balancing parents’ and children’s rights;
- d) *Enabling preferences to minimize regrets* where staff ensure that families are facilitated to be involved in the child’s care in a way that brings whatever comfort and reassurance is possible within this very challenging experience.

Considering these activities, the perception of staff as an “instructor” within children’s EOLC no longer fitted and so the concept of “guide” was developed, as one who is knowledgeable about the liminal space of children’s EOLC and who will use that knowledge to enable and reassure families, opening up possibilities that they did not or could not know were available. The culminating effect of the interdisciplinary team assuming the role of guides and creating a spontaneous support structure for families at EOLC forges relationships built on a shared humanity between parents and staff.

The foregrounding by parents of these alternative stories within this study through a second narrative reading of the texts, served to identify staff as “witnesses” to the immense and deep suffering that parents’ experienced. Parents recognised that staff were undertaking what was difficult and challenging work, and yet took time to demonstrate a personal level of caring, for example by coming to see a child before it left the hospital to go home to die, or by their tears as a child died. Through witnessing staff’s demonstrations of humanity in recognising the child as a worthy individual, or honouring the informal ceremonies or rituals created by families to publicly demonstrate their love for their child, parents experienced a deep sense of connection with staff and felt that staff understood the enormity of their loss. This “witnessing” by staff suggested ways in which staff can fulfil this important function for families, creating new conversations that centre and reinforce the family’s role in their child’s EOLC, even within a hospital setting. The shared sense of humanity at the impending death provided parents in this research with a sense of reassurance, that the world, as represented by the hospital staff, had some understanding of the depth and complexity of their loss. It also reflects the social constructionist perspective that the meaning of the death of this child is formed within social relationships, in this context between the parents and staff and in this way the death is reflected as a loss to “the world”, and not just this family.

As evidenced in the discussion in Chapter 5 of the findings from the parents’ interviews, the importance of care that is based on the shared humanity of parents and staff, and a shared sense of loss that a child is dying, along with excellent medical and nursing care, were highlighted as significant by parents, as they endeavoured to reconnect with their role as the child’s parent during EOLC. Parents’ highlighted activities and actions that re-centred their important relationship with their child. The importance of this re-centring of the parental role, as staff ensure parents have maximum physical and emotional connection to their child, can restore a sense of choice and agency for parents in relation to how their child dies. By facilitating this, staff allow the possibility that parents can experience EOLC as bringing comfort and meaning in their bereavement. This approach stems from a shared sense of humanity between the families and staff in recognising the profound and life altering experience of the death of a child.

8.5. Scaffolding for Meaningful Family Experiences in EOLC

Having recognised the lasting meaning for parents from the stories of deep human connection that were highlights by the enabling experiences parents described, these stories were then analysed using concepts from narrative practice. Drawing on narrative practice and supported by evidence from this research, key concepts of “enabling/reassuring conversations”, “definitional rituals” and “remembering conversations” were developed to provide parents and family with care that is empowering and supportive and encourages agency within this very difficult experience. Throughout all of this experience, the importance of relationships built between families and staff is central, and the relationship-based approach to care is critical, demonstrating to parents a “human touch” as they recognised staff’s care for them and their child on a human as well as a professional level.

These findings were used to create the structure of a “Map of Narrative Practice in Children’s End-of-Life Care” in order to provide a conceptual framework that can be used by the interdisciplinary team providing care to children and families at this time. As described in Chapter 7, this Map brings together the key findings of this research. Set within the context of both national policy and the community and cultural context of each family, it highlights the view of EOLC as an experience of liminality, with parents undergoing new and confusing experiences as they navigate this experience. At this time, the focus of care moves away from curative medical and nursing interventions. The Map recognises the essential role of all the staff as guides to the family, within this liminal space, providing gentle guidance through conversations that are enabling and reassuring, honouring family rituals and engaging in remembering conversations that celebrate the child’s life. Providing a spontaneous support structure, staff join the family through a shared sense of humanity to recognise the tragedy that is the death of a child not just to the family, but to the world. The Map of Narrative Practice in Children’s End-of-Life Care integrates the findings of the research and fulfils the final objective of this study which is to bring the experiences of parents and staff forward into the planning and development of best practice for hospital based EOLC care for families in the context of the new CHI hospital.

8.6. Implications for Practice

The creation of the Map of Narrative Practice in Children’s End-of-Life Care from the findings of this research brings a deeper understanding of the experiences of parents and staff during this life-altering experience for families. It expands on the existing knowledge of the experiences of both parents and staff and proposes a model of narrative and relationship-based care. Central to this approach is an appreciation of the profound life event that families go through, where they leave behind the known world where the child was alive to becoming a parent whose child had died. The research highlights the importance of all team members demonstrating a human understanding of this life changing experience by bearing witness to parents’ suffering and immense love for their child. This level of care is scaffolded by concepts adapted from narrative practice which can be implemented by all team members, strengthening the interdisciplinary approach to psychosocial care at end of life.

The development of this Map of practice will allow for the sharing of the findings of this study within the practice of EOLC in Ireland. The findings have been endorsed by the Expert Advisory Group for this project. As an initial step, in the dissemination of the findings to support service developments the findings can be presented to the EOLC committee at the research site. As the new Children’s Health Ireland hospital will care for the largest number of dying children and their families in Ireland, it is hoped that the findings of this study will contribute to the development and implementation of EOLC for children and families at that site and support the new “National Mode of Care for Paediatric and Neonatal Healthcare Services” in Ireland (Nicholson et al 2017).

A key strength of this research is the development of a practice model that promotes optimum collaboration between parents and the interprofessional team who cares for their child in order to promote excellence in the provision of children’s EOLC. As this practice-based framework has potential to better support families at a critically difficult time in their lives, it is essential to introduce the framework to EOLC practitioners across disciplines and support them in adopting it in practice. The dissemination plan for this research will include a number of approaches:

- The research findings will be widely disseminated within the research site and the wider CHI group to inform policy and practice. An executive summary of the research, together with proposals for service development based on the findings, will be presented to senior management and local and cross-site committees.

- Presentations and other teaching resources (both face to face and on-line) will be developed to introduce and explore the implications of this research and application of the framework in the context of children's EOLC. Workshops to introduce the framework may be co-facilitated by a colleague from another discipline to promote inter-disciplinary adoption of the framework.

- The research findings will form the basis of academic papers to be submitted for publication to peer reviewed inter-disciplinary journals to ensure the widespread dissemination of this approach to care in children's EOLC.

Taken together, these approaches will allow for the widespread dissemination of the findings of this research, integrating the voices of the research participants into improved practice going forward.

8.7. Limitations of the Study

Within any study, the limitations inherent in the research need to be acknowledged. This was a small study which took place on a single site, posing possible concerns that the views expressed would not reflect the breath of opinion in this field. The study also included children whose deaths have occurred from multiple causes, raising concerns that the parents' experiences would not be similar enough for meaningful comparison. The research was also set in a particular point of time with field work being undertaken from April 2019 to April 2020.

Due to the sensitive nature of the subject being studied, and in order to ensure that the participants were safe in their participation, an approach using gatekeepers for the recruitment of the parent participants was used, possibly excluding some families who might have wanted to have been involved, due to the gatekeepers' concern about their vulnerability. While the data gathered resulted in rich and descriptive findings, this research cannot provide any statistical information in relation to the experience of bereaved parents.

It should also be acknowledged that this research was originally designed to include the experience of bereaved siblings. However, due to recruitment difficulties mainly due to parents' concern that siblings' participation might be upsetting for them, an insufficient

number of siblings were recruited for the study. It is important to recognise that the absence of the voice of the siblings may have impacted on the findings from this research militating against the inclusion of their needs within the theoretical framework developed. This is an important area that could be very usefully explored in future research.

The arrival of the COVID Pandemic in March 2020 impacted on the study in two ways. Firstly, feedback to parent participants and member-checking took place during this period. As the postal service was in disarray, there is no way of knowing if the letters to parent participants were delivered. Equally it could be speculated that a low level of feedback from parents could be due to the impact of COVID on their lives and lack of time or energy to reply to the request for feedback. The second impact involved the need for me to take a six-month break period from my PhD research in March 2020 as I returned full time to my position as a health care worker. Because of the high demands of work during that period, it would not have been possible to continue my research. I returned to work on the completion of this study in September 2020.

8.8. Conclusion

This study has undertaken an in-depth exploration of the experiences of bereaved parents and the staff who care for them during the EOLC of their child. A body of published research exists within the field predominantly from medical and nursing perspectives and is dominated by studies with families of children who experience childhood malignancies. The present research, however, focused on the psychosocial care provided and received within children's EOLC from a sociological perspective, adopting a social constructionist perspective of death and bereavement and including parents of children who have died for a wide range of causes. The use of a narrative methodology generated findings that reflected the dominant themes from the literature but also allowed for the identification and exploration of new key findings. Using a narrative frame for this study allowed for the possibility of understanding the stories of study participants as "intentional, agentic, and responsive to hardships in order to remain connected to beliefs, hopes and values" (Lainson, 2020, p. 300), providing voice to an area of experience that is perceived as sensitive research within the field.

These key findings emerged from an in-depth exploration of parents' experience, identifying it as a rite of passage, a "liminality" experience of moving from the familiar and known world into the complex and demanding "betwixt and between" world that is

experienced when their child is dying. The anthropological concepts of “spontaneous communitas” and “instructors” were used as a lens to explore and discuss the role of staff at EOLC. This generated findings about the evolving role of staff within EOLC, as they move from the expert position akin to the anthropological concept of instructor to positions of guide and witness where the staff function to witness and support the suffering that parents endure, forming a “spontaneous support system”. It is therefore recognised that staff not alone provide professional expertise in the EOLC of the child but fulfil a broader role as guides to parents in availing of opportunities and creating alternative possibilities for meaningful time with their children. This is achieved through collaborative conversations with parents based on a “shared humanity” within the experience of the death of a child.

With these findings in mind and using the lens of narrative practice, a Map of Narrative Practice was developed to suggest ways that interdisciplinary teams can promote the development of alternative possibilities and agency with children’s EOLC. In addition, implications of the research findings for practice within the new national framework for children’s healthcare being developed in Ireland were discussed.

8.9. Epilogue and Reflection

As a practitioner researcher, the undertaking of this project has been fascinating, challenging, frustrating and enriching all at the same time. As with any PhD study, it has taken its own unpredictable journey, bringing me, as a researcher, experiences that were unexpected yet enriching at the same time. To be able to stand with and listen to parents relay the stories of their experience of EOLC care has been a privilege, coloured by the challenge of listening to their deep levels of emotion both when I was with them during interviews and as I faithfully transcribed their words into “text”. Along the way, I have become changed as a researcher, a practitioner and as a person, enriched and informed by this process, gaining an in-depth understanding of parents’ and staff experiences and challenges in the world of children’s end of life care that I will take with me back into my practice.

But what remains with me and I will take forward into the dissemination phase of this project is how parents’ experience can be influenced by staff who care for them at EOLC. In returning to Mags’ story in the Prologue of this study, I now understand that, when the nurse made such an effort to find that toast for her, Mags, the mother of a little boy who

was dying, experienced a sense of understanding that went beyond the professional role of the nurse. This experience demonstrated to Mags that the nurse acknowledged the gravity of their family situation and shared with them a deep understanding of the meaning of their child's impending death. Having completed this study, I now understand that, in organising the gift of the toaster and the mugs for the staff, Mags recognised that act of stepping beyond the professional role and joining the family to share their sense of sorrow. In her own way, Mags was recognising this gesture of shared humanity. This sense of shared humanity at the death of a child had been reflected within the research and has become one of its key findings.

It is through the insights from the many stories in this research that we can go forward to improve practice, so that each family whose child dies within a hospital can experience this sense of enhanced care and shared humanity that comes with the inclusion of a psychosocial aspect to care, in addition to expert medical and nursing care. In thinking about how this might be done, I am reminded of Cheryl White's (2011) suggestion when she reflected on how Michael's White work might be honoured after his death. She talked about the idea of "opening spaces" to include "those who are not currently a part of our mainstream professional culture" and who have stories to offer about what good practice would look like within their own context (p. 182). She asks "What would it mean if those voices were given a space on the stage?" (p. 182). In bringing the voices of parents and staff on to "the stage" of children's EOLC in Ireland, I believe that this research has demonstrated how those stories can enrich and improve the care provided to families experiencing the death of a child in a hospital.

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APPENDICES

Appendix 1: Classification of Children Requiring Palliative Care

- “**Group 1 - Life-threatening conditions** for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails: for example, cancer, irreversible organ failures of heart, liver, kidney.
- **Group 2 - Conditions where there may be long periods of intensive treatment** aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible: for example, cystic fibrosis, muscular dystrophy.
- **Group 3 - Progressive conditions** without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years: for example, Batton’s disease, mucopolysaccharidosis.
- **Group 4 - Conditions with severe neurological disability** which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not considered progressive: for example, multiple disabilities, such as brain or spinal cord injuries, including severe cerebral palsy.”

ACT & RCPCH (1997, 2003) quoted in Price J. & McFarlane (2009) p. 4.

Appendix 2: Literature Search Strategy

The literature search was carried out in December 2017/ January 2018. The databases searched were CINAHL, PsychInfo, ASSIA, PubMed and Social Science Full Text. Following the outlining of the research questions to be used in the search, the question used to involve the search terms were:

Parent: What are the experiences of parents during children's hospital-based EOLC?

Staff: What are the experiences of staff during children's hospital-based EOLC?

From these questions, the following terms were developed for the search strategy:

Area of Search	
Parents	[end of life OR terminally ill OR terminal care] [paediatric OR pediatric OR child*] [experience* OR perception* OR attitude* OR view* OR feeling*] [parent* OR mother* OR father*]
Staff	[end of life OR terminally ill OR terminal care] [paediatric OR pediatric OR child*] [experience* OR perception* OR attitude* OR view* OR feeling*] [health care worker* OR health care professional*]

All searches were filter for the following:

- Time period: 2000-2017
- Peer Reviewed
- Language: English

In total these searches yielding the following results:

<i>Topic</i>	<i>Total number of articles Reviewed using Title/ Keywords/ Abstracts</i>	<i>Duplicated</i>	<i>Total Number of Articles Reviewed</i>	<i>Sub-total</i>	<i>Excluded</i>	<i>Total</i>
Parents – 2000 - 2017	143	4	139			
Parents – 2018-2020	18	-	18	157	17	140
Staff - 2000 - 2017	144	12	122			
Staff – 2018 – 2020	42	4	38	160	99	61

The following categories of articles in the literature search were excluded: medical interventions for the child at EOLC; neonatal death in a maternity hospital; bereavement experience for parents; experience of parents who lose adult children of adult children who die, as they were outside of the scope of the study. In addition, approximately 40 further articles or book chapters were identified (through references and citations searches) during the study that were pertinent to this literature review.

Appendix 3: Interview Schedules

Interview Schedule – Parents

Preparation

- a. Review of Participant Information Sheet and ensure the participant understands the context and process for the research and interview
- b. Consent Signed
- c. Explanation of recording and testing of same

Initiation

- a. Posing of the initial topic for narration

'Can you please tell me about your experience of the end of life care and death of your child, exploring what was challenging for you at the time and what helped, and what was more difficult for you as a parent during that time' [parent question]

'Can you please tell me your experience of caring for a child at the end of life care and death, exploring what you believe was helpful or difficult for families during that time' [staff question]

- b. Using visual aids: the questions can will be printed out for interviewee to review while telling the story

Main Narration

- No interruptions by the researcher
- Non-verbal encouragement to continue story-telling
- Wait for the coda

Questioning Phase

- Only 'what happened then?'
- No opinion and attitude questions
- No contradictions
- No why questions

During this phase, the researcher will ask questions to clarify issues raised by the interviewee during the story telling. Any questions will relation to the story provided by the interviewee. As a final question, the researcher will ask the interviewee what it has been like for them to tell their story.

Concluding talk

- Stop recording
- Why-questions allowed
- Thank the interviewee for their participation and ensure that appropriate support is arranged if they have found the interview upsetting
- Memory protocol (in which the researcher makes notes of their own experience of the interview) immediately after interview

(*designed from Jovchelovitch & Bauer, 2000*)

Interview Schedule - Staff Focus Groups

Preparation

- a. Review of Participant Information Sheet and ensure participants understand the context and process for the research and interview
- b. Consent Signed
- c. Explanation of recording and testing of same

Initiation

- a. Explanation of group process explaining that the group is requested to allow each member to give their account of the question without interruptions, with general discussion at the end of the group
- b. Posing of the initial topic for narration
'Can you please tell me about your experience of caring for a child at the end of life care and death, exploring what you believe was helpful and what was difficult for families during that time'
- c. Using visual aids: the questions can will be printed out for interviewee to review while telling their story

Main Narration

- No interruptions by the researcher
- Non-verbal encouragement to continue story-telling
- Wait for the coda

Questioning Phase

- Only 'what happened then?'
- No opinion and attitude questions
- No contradictions
- No why questions

During this phase, the researcher will ask questions to clarify issues raised by the interviewees during the story telling. Any questions will relation to the story provided by the interviewees. As a final question, the researcher will ask the interviewee what it has been like for them to tell their story.

Concluding talk

- Stop recording
- Why-questions allowed
- Thank the interviewee for their participation and ensure that participants are aware of the support available to them if they have found the interview upsetting
- Memory protocol (in which the researcher makes notes of their own experience of the interview) immediately after interview

(*designed from Jovchelovitch & Bauer, 2000*)

Appendix 4: Gatekeeper Information Sheet



Gatekeeper Information Sheet

TITLE OF THE STUDY: "Gathering the Voices of Parents, Siblings and Staff to inform End of Life Care Policies at a Children's Hospital".

Thank you for taking the time to consider assisting me in conducting a research study. Before you decide, it is important to understand why the research is being done and what it would involve for you and for the participants. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Please take time to decide if you are might be able to facilitate this research.

WHO I AM AND WHAT THIS STUDY IS ABOUT?

As Bereavement Co-ordinator at Temple Street, I believe that it is very important to capture the voices of bereaved parents, siblings and staff to inform the services provided to these families going forward into the New Children's Hospital. The research that will gather this information as part of a PhD programme I am currently undertaking in Trinity College, Dublin (funded by the National Children's Research Centre). The aim of this study is to explore the experience of parents and siblings provided with psychosocial care in an acute children's hospital during the end of life care of their child and take from those experiences recommendation for best practice for end of life psychosocial care of families going forward into the New Children's Hospital which is planned for Dublin. The study will have received approval from the Ethics Committee at Temple Street Children's University Hospital as well as the School of Social Work and Social Policy, Trinity College, Dublin, before commencing.

WHAT I NEED YOUR ASSISTANCE WITH?

I am asked for your involvement in recruiting suitable parents and siblings to become involved in the research through individual interviews (parents) and focus groups (siblings). The decision to participate as a Gatekeeper is entirely voluntary and will not impact of your relationship with myself, the department or the hospital in any way. Due to the sensitivity of the subject matter, your involvement in recruiting participants and in supporting them after the research interview/ focus group is very important.

I will be asking you to identify suitable families from the criteria set out below, and to telephone the parents to explain the parameters of the research and invite them to consider participating. I will then be asking that you provide the researcher with their name of the participating families and appropriate contacts, so that the researcher can follow up. I will be asking you to be available to the parent(s) and sibling(s) to provide support after their participation in the research to ensure that they did not find the experience upsetting.

WHAT FAMILIES ARE SUITABLE FOR THE RESEARCH?

I am seeking a total of 10-15 parents and 10-15 siblings to be involved in the research with the following inclusion/exclusion criteria:

Inclusion/Exclusion Criteria for Study Participants

Group	Inclusion Criteria	Exclusion Criteria
Families	- Families will be 6 months to 2 years post bereavement, with the provision that a family who agrees to be involved with the research but are not ready to do so until outside of this	- Any family who may attribute the cause of their child's death to the Hospital that is the setting of the research - Families whose child had died where the Child Protection services were involved before or after the death

	<p>timeframe will be facilitated, if possible;</p> <ul style="list-style-type: none"> - Families will have had a child who has been provided End of Life care for by the Hospital, and has died, regardless of the location of death; - The cause of death will be inclusive so that families whose child has died of an accident, SIDS, sudden onset acute illness or were born with or developed a life limiting condition will be eligible to be included; - Be sufficiently fluent in English so that the gate keeper and interviewer can be satisfied that their experience and perspective can be full understood, and that their language capabilities do not diminish the ability to capture that perspective. 	<ul style="list-style-type: none"> - Families where the researcher has been the primary provider of psychosocial support during end of life care and bereavement
Parents	<ul style="list-style-type: none"> -Parents or carers of the child who has died - Over 18 - Can be parents of other living children or not - Parents from a broad background of nationalities, cultures, religions and life experiences 	<ul style="list-style-type: none"> - An active psychiatric condition or additional social challenges - Any parent whom the social work gatekeeper or researcher believe could be adversely affected by participating in the research
Sibling	<ul style="list-style-type: none"> - Age 6 to 18 at the time of recruitment; - Parental consent required - Parents will be invited to explain to the sibling the purpose and outline of the research. Consent from parents for their child's participation will be sought by researcher. - Researcher will also meet the child and outline for them the outline and purpose of the research before the focus group commences and seek their assent 	<ul style="list-style-type: none"> - Demonstrating signs that they are struggling with their bereavement (i.e. in need of level 3 or 4 support on the Irish Childhood Bereavement Care Pyramid – see Appendix 19) - Any child currently attending the Child and Adolescent Mental Health Service - Any child or adolescent experiencing Complicated Grief or whom the social work gatekeeper or researcher believe could be adversely affected by participating in the research

Participation by both parents and siblings in the same family is not a criterion for inclusion in the research and the researcher fully expects that there will be parents from some families who are involved and not the surviving children and in other families siblings may be willing to be involved when parents are not.

WHAT WILL TAKING PART IN THE RESEARCH INVOLVE?

During the research interview or focus group, individual will be asked to speak about their experience of end of life care in the Hospital. A narrative methodology had been adopted for this research which encouraged participants to tell their own story in a very open format. Parents will be invited at the beginning of the interview to tell the story of the end of life care and death of their child, emphasizing what supports they found helpful during that process. Supplementary questions will be asked by the interviewer after they have told their story in order to elaborate on the topics parents have raised. For adult participants it is expected that the interviews will take approximately one to one and a half hours, and will take place in the hospital, parents home or another venue that feels safe for the parent.

For the children, they will all be invited to attend focus group that will take place in the hospital. For children, as somewhat more structured approach will be used in order to ensure that they feel safe in the focus group environment. In order to ensure children's physical and emotions safety, members of the medical social work team will be invited to co-facilitate these focus groups.

For all participants, participation in the research is entirely voluntary and consent to involvement can be withdrawn at any time prior to interview, during the interview process or after the interview has been completed. The well-being of the participants will be to the fore at all times during the research.

WHO WILL HAVE ACCESS TO DATA FROM RESEARCH?

Following the interviews/focus groups, all materials will be transcribed and anonymised by the researcher. No-one except the research and the researcher's supervisor will have access to the anonymised transcripts. However, should issues of participant safety arise during the interview process, from a mental health or child protection perspective, participants will be informed that the researcher will be obliged to share these concerns with her supervisor in order to ensure that appropriate steps are taken to keep the participant safe. Any such course of action will follow procedures already in place in the Hospital to address these issues.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

Following the analysis of the anonymised transcripts the findings of the study will be used for the following purposes:

- Writing up and completion of the requirement of the PhD study being undertaken
- Dissemination through reports and recommendations developed internally within the site and within the Children's Hospital Group
- Sharing of findings through conferences, publications and teaching.

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

Please feel free to contact myself as the researcher or my supervisor should you have any further questions:

*Researcher: Anne Marie Jones, Temple Street Children's University Hospital: (087 6711575)
annemarie.jones@cuh.ie*

College Supervisor: Dr Erna O'Connor, Trinity College, Dublin: erna.oconnor@tcd.ie

Many thanks for taking time to read this information about the research and for considering participation as a Gate Keeper.

Appendix 5: Participant Information Sheet (Parent)



Participant Information Sheet (Parents)

TITLE OF THE STUDY: "Gathering the Voices of Parents, Siblings and Staff to inform End of Life Care Policies at a Children's Hospital".

My name is Anne Marie Jones and I am currently undertaking a research study with families who have experienced the death of a child. I appreciate that this has been a very difficult time for your family, but also believe that bereaved families have important experiences to contribute to the development of services in a children's hospital. Before you decide whether or not to participate, it is important to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Please take time to decide whether or not to take part.

WHO I AM AND WHAT THIS STUDY IS ABOUT

As Bereavement Co-ordinator at Temple Street, I believe that it is very important to capture the voices of bereaved parents, siblings and staff to inform the services provided to these families going forward into the New Children's Hospital. This research that will gather this information as part of a PhD programme I am currently undertaking in Trinity College, Dublin (funded by the National Children's Research Centre). The aim of this study is to explore the experiences of parents and siblings provided with psychosocial care in an acute paediatric hospital during the end of life care of their child, and develop from those experiences recommendations for best practice for end of life psychosocial care of families going forward into the New Children's Hospital which is planned for Dublin.

WHAT WILL TAKING PART INVOLVE?

For parents, taking part in this research will mean being interviewed by myself around your experience of end of life care. You will be asked to tell the story of your experience around the time of and since the death of your child as is comfortable for yourself. I will ask some questions that will expand on the areas you have raised during your interview for clarification or further exploration. I will also gather some basic information about your child who has died (date of birth, date of death and cause of death), yourself (your age, the location that you live in, your work etc) and your family (who else is in the family, age, etc). These interviews will take place in the Hospital or, if you feel more comfortable, in your home or other location.

For siblings, it is more appropriate to gather their views in a children's group which will take place at a convenient time in the Hospital. Groups of 4-5 children will be interviewed together and be asked questions about their experience around the end of life care and death of their sibling. A member of the medical social work team will also be in attendance at that focus group to support the children, to help me make it a comfortable and relaxed experience and to facilitate the research process.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been asked to take part in the research because your child, who was a patient of Temple Street, has sadly died. I know this has been a very difficult experience for yourself and your family. As a researcher, I believe that it is very important to include the voices of bereaved parents and siblings, as they feel ready, to ensure that your experiences can inform the planning process going forward into the New Children's Hospital making sure that the best possible services can be planned for families who find themselves going through this difficult experience in the future.

DO YOU HAVE TO TAKE PART?

Involvement in this research is entirely voluntary and your decision to participate or not to participate will not in any way effect your relationship with Temple Street Hospital. You may wish to be involved yourself and you may feel it is appropriate for your child's siblings to be interviewed. However, the research does not require the involvement of both parents and siblings. Your written consent will be sought before you become involved and you can withdraw that consent at any time, before or during the interview, or anytime afterwards by contacting the researcher. You also have the right to not answer any questions that might be uncomfortable or too upsetting for you.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

We are currently at a unique time in the development of children's hospital services in Ireland. The findings of this research will be brought forward to inform the development of end of life services in the New Children's Hospital. It will add to the small body of research in Ireland carried out with bereaved families. There is a body of evidence that bereaved families like to contribute to research. Parents report that this experience honours the short lives of their children and that parents can contribute to the knowledge available about the experiences of families whose child had died and improving services for families who find themselves in this situation in the future.

However, I would ask you to consider your involvement carefully and ensure that you feel it is appropriate to be involved at this time as I appreciate that the subject matter is very sensitive and might be upsetting. The Medical Social Worker from Temple Street who is working with your family will be available at any point after your interview or your child's if they are being interviewed to provide support for any aspect of the interview that might have been upsetting.

WILL TAKING PART BE CONFIDENTIAL?

All of these interviews/ children's groups will be audio recorded using a digital recording device and transcribed into a written form. All identifying information (for example your name, child's name, location where you live, identifying circumstances around the death) will then be taken out and an anonymous code used that will be kept securely and only known to the Researcher. The transcript of your interview or your child's group interview will be seen by the researcher and their supervisor and the identity of the person being interviewed will not be known to anyone except the researcher.

In exceptional circumstances, if the researcher has a strong belief that there is a serious risk of harm or danger to either the participant or another individual (e.g. physical, emotional or sexual abuse, concerns for child protection, self-harm, suicidal intent) or if a serious crime has been committed, confidentiality will have to be broken and the appropriate services contacted. Should such a circumstance arise, the researcher would discuss it with yourself and will adhere to normal hospital practices to address the issue.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

Any identifying information that you provided to the researcher (including signed consent forms and original audio recordings) will be kept securely in a locked cabinet or on a password protected computer within the hospital for the duration of the researcher's study. This information will require to be retained for a period of 5 years. The typed transcripts of the interviews will be available to myself and my research supervisor, Dr Erna O'Connor in Trinity College. Excerpts from your interview or from the group your child may be involved with, which have been completely anonymised, with all identifying information taken out, may be used as examples in academic writing, published articles, conference presentations or for teaching purposes. The reason for doing this is to ensure that the actual words participants provide powerful evidence for the findings of the study and serve to share with current and future service providers the real experience of families in your circumstances.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

Following the analysis of the anonymised transcripts, the findings of the study will be used for the following purposes:

- Writing up and completion of the requirement of the PhD study being undertaken;
- Dissemination through reports and recommendations developed internally within Temple Street and within the Children's Hospital Group;
- Dissemination through reports and recommendations to a broader audience nationally (and internationally) if invited;
- Sharing of findings through conferences, publications and teaching.

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

For any further information please feel free to contact the researcher on the

Researcher: Anne Marie Jones, (Temple Street Children's University Hospital); 087 6711575; annemarie.jones@cuh.ie

Supervisor: Dr Erna O'Connor, Trinity College; erna.oconnor@tcd.ie

Many thanks for taking the time to read this sheet and consider whether or not you would like to be involved in this research.

Funding to undertake this research has been provided by the National Children's Research Centre

Appendix 6: Participant Information Sheet (Staff)



Participant Information Sheet (Staff)

TITLE OF THE STUDY: "Gathering the Voices of Parents, Siblings and Staff to inform End of Life Care Policies at a Children's Hospital".

My name is Anne Marie Jones and I am currently undertaking a research study with families who have experienced the death of a child. During this study, it is also important to explore the experiences of staff caring for those families. I am requesting your participation to share your experience as a staff member who cares for children and their families at the end of the child's life. Before you decide whether or not to participate, it is important to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Please take time to decide whether or not to take part.

WHO I AM AND WHAT THIS STUDY IS ABOUT

As Bereavement Co-ordinator at Temple Street, I believe that it is very important to capture the voices of bereaved parents, siblings and staff to inform the services provided to these families going forward into the New Children's Hospital. This research that will gather this information as part of a PhD programme I am currently undertaking in Trinity College, Dublin (funded by the National Children's Research Centre). The aim of this study is to explore the experiences of parents and siblings provided with psychosocial care in an acute paediatric hospital during the end of life care of their child, and the staff who work with them and develop from those experiences recommendation for best practice for end of life psychosocial care of families going forward into the New Children's Hospital which is planned for Dublin.

WHAT WILL TAKING PART INVOLVE?

For staff, taking part in this research will mean being interviewed by myself around your experience of end of life care in a focus group. You will be asked to tell the story of your experience around the time of caring for a child at end of life care as is comfortable for yourself. I will ask some questions that will expand on the areas you have raised during your interview for clarification or further exploration. I will also gather some basic information about yourself (your age, your professional qualifications, number of years working on the job). Focus group interviews will take place in the Hospital, in a quiet area away from your area of work. Should it prove difficult for you to attend a focus group, an individual interview may be organized.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been asked to take part in the research because you work with children and families at end of life care at Temple Street. I very much appreciate that this is difficult and challenging work but believe it is very important to capture the experiences of staff in this work to add to the research findings going forward.

DO YOU HAVE TO TAKE PART?

Involvement in this research is entirely voluntary and your decision to participate or not to participate will not in any way effect your relationship with the hospital bereavement co-ordinator or the medical social work department. Should you agree to participate, your written consent will be sought before you become involved and you can withdraw that consent at any time, before or during the interview, or anytime afterwards by contacting the researcher. You also have the right to not answer any questions that might be uncomfortable or too upsetting for you.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

We are currently at a unique time in the development of children's hospital services in Ireland. The findings of this research will be brought forward to inform the development of end of life services in the New Children's Hospital, as well as add to the small body of research in Ireland carried out with bereaved families, and the staff who work with them.

It is important to consider your involvement carefully and ensure that you feel it is appropriate to be involved as I appreciate that the subject matter is very sensitive and might be upsetting. I will be happy to say after the focus group to chat with any staff member who found the group upsetting, and the occupation health department/ HSE staff support services are also available for staff should the experience provide challenging. Every effort will be made to make the focus group/ interview comfortable for all involved.

WILL TAKING PART BE CONFIDENTIAL?

All of these interviews/ focus groups will be audio recorded using a digital recording device and transcribed into a written form. All identifying information (for example your name, and personal identifying information etc.) will then be taken out and an anonymous code used that will be kept securely and only known to the Researcher. The transcript of your interview will be seen by the researcher and their supervisor and the identity of the person being interviewed will not be known to anyone except the researcher.

In exceptional circumstances, if the researcher has a strong belief that there is a serious risk of harm or danger to either the participant or another individual (e.g. physical, emotional or sexual abuse, concerns for child protection, self-harm, suicidal intent) or if a serious crime has been committed, confidentiality will have to be broken and the appropriate services contacted. Should such a circumstance arise, the researcher would discuss it with yourself and will adhere to normal hospital practices to address the issue.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

Any identifying information that you provided to the researcher (including signed consent forms and original audio recordings) will be kept securely in a locked cabinet or on a password protected computer within the hospital for the duration of the researcher's study. This information will be retained for a period of 5 years. The typed transcripts of the interviews will be available to myself and my research supervisor, Dr Erna O'Connor in Trinity College. Excerpts from your focus group or interview, which have been fully anonymised, with all identifying information taken out, may be used as examples in academic writing, published articles, conference presentations or for teaching purposes. The reason for doing this is to ensure that the actual words of participants provide powerful evidence for the findings of the study and serve to share with current and future service providers the real experience of working with families in these circumstances.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

Following the analysis of the anonymised transcripts, the findings of the study will be used for the following purposes:

- Writing up and completion of the requirement of the PhD study being undertaken;
- Dissemination through reports and recommendations developed internally within Temple Street and within the Children's Hospital Group;
- Dissemination through reports and recommendations to a broader audience nationally (and internationally) if invited;
- Sharing of findings through conferences, publications and teaching.

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

For any further information please feel free to contact the researcher on the

Researcher: Anne Marie Jones, (Temple Street Children's University Hospital); 087 6711575; annemarie.jones@cuh.ie

Supervisor: Dr Erna O'Connor, Trinity College; erna.oconnor@tcd.ie

Many thanks for taking the time to read this sheet and consider whether or not you would like to be involved in this research.

Funding to undertake this research has been provided by the National Children's Research Centre

Appendix 7: Sample of Coding Process

Data Source	Transcript Extract	Open Coding	Candidate Code	Theme Review	Defining and Naming Themes
Parent Interview	<p>“We’re gonna do this next but this might happen” “we’re gonna do this next but this might happen, you need to be prepared for the worst at every time”. And we were desperately upset ...” (Par013)</p>	Medical Uncertainty	<i>Facing Medical Uncertainty</i>	Recognising the unknown future for their child	<i>“Being” in a Liminal Space</i>
HCP Focus Group	<p>“And again like it was because we had planned it, [...] we had stopped all of that [monitoring] because our plan, it was there and it allowed the girls to know that “no we are not doing obs, we are just doing comfort measures” and the baby can stay where she needs to stay like so and “yes it’s ok if a suction is needed you can suction there on mammy’s chest and leave her alone”. So, like that, the plan</p>	Importance of End of Life planning	<i>Staff Practices to promote End of Life Care</i>	Staff Implementing End of Life Care:	<i>Recognising the need for End of Life Care</i>

	<p>was really really good cause it gave everyone confidence em ... with it, and that death went as smoothly as deaths can go like [nervous laugh]" [StCNM001]</p>				
<p>Social Work Focus Group</p>	<p>"And that they are still that child's parents, and that they are still ye know up until that moment that that child had died, they have done everything for them, made all the decision and that at that point when the child died the decisions that have to be made about their child, there is a legal process, but that's still their child." (StSW20)</p>	<p>Legal Requirements</p>	<p><i>Medicolegal Discourse</i></p>	<p>Competing Discourses</p>	<p>Negotiating competing discourses</p>

Appendix 8: Participant Welfare Statement



Participant Welfare Statement

Research Study:

“Gathering the Voices of Parents, Siblings and Staff to inform End of Life Care Policies at a Children’s Hospital”

It is recognised that, while undertaking research, participants may disclose situations that have the potential to place themselves or others at risk. This protocol applied to all participants in the study, adult or child. However, with the involvement of children in research, it is critical to recognise the possibility that the researcher may encounter a situation that places a child at risk of harm from physical, emotional or sexual abuse, or may place the child’s welfare at risk. In such a situation, the researcher must recognise their responsibility from a child safeguarding perspective.

Should such a situation arise where the researcher encounters a concern about a participant being at risk themselves, or a risk to others, the following procedure will be followed by the researcher for any participant (adult or child):

1. Participant welfare is of paramount importance during this study.
2. Information provided by a participant to the researcher will be kept in the strictest confidence and any information from the interview will be anonymised before being used.
3. In exceptional circumstances where the researcher has a strong belief that there is a serious risk of harm or danger to either the participant or another individual (e.g. physical, emotional or sexual abuse, self-harm, suicidal intent) or if a serious crime has been committed, confidentiality will have to be broken and the appropriate services contacted. Should such a circumstance arise, the researcher will discuss it with the participant (and their parent if appropriate), consult their supervisor and, if deemed appropriate, take whatever action is required to keep a research participant safe.
4. Child Welfare: The child’s welfare and safety are of paramount importance in this research process and the researcher is committed to ensure that all appropriate guidelines to keep children safe are adhered to during this study.
 - a. Should a child participant disclose during the process of involvement in this research that they are at risk of abuse as defined above, then the researcher will be obliged to break that confidentiality in order to make sure the child is safe. This will be outlined to the child participant before the research commences.
 - b. Should a concern about child welfare or protection arise during the course of the research, the researcher will discuss any concerns with her Academic Supervisor, Dr Erna O’Connor, to review the context and nature of the concern. However, if the child is in immediate danger and supervisor is not available, the researcher will approach the Senior Medical Social Worker in Child Protection, Michelle Strahan, at Temple Street Children’s University Hospital (TSCUH) for consultation and advice or another senior social worker in her absence;

- c. Wherever possible, the child will be informed by the researcher of their concerns and involved in the addressing of this issue and the plan to ensure they are safe.
- d. Equally, parents will be informed by the researcher of the concerns and the plan to address same will be outlined to them.
- e. The researcher will follow the protocol outlined in TSCUH's Safeguarding Statement and Children First Guidelines 2015 (Department of Children and Youth Affairs).
- f. As a professional social worker, the researcher is cognisant of her responsibilities as a Mandated Person under Children First Act 2015 and recognised that the safety of the child involved overrides any considerations from a research perspective.

Each research participant of this research will be appraised of this limitation of confidentiality before agreeing to participate in this research project.

Anne Marie Jones, Researcher, August 2018