

Mothers Experiences of Hospice in the Care of their Child: An Interpretive  
Phenomenological Analysis of Reflective Diaries and Interviews.

By

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A Poem Inspired by the River Loire

Sitting by its banks, listening to the  
Ripples of timeless flow  
The sun's rays glistening on the water  
Like an illuminating show

The butterflies come to greet me  
Their wings fluttering in the breeze  
The waters seem to call me  
Closer I get, in response to their tease.

The icy cold waters beneath, tickle my toes  
Washing over these tired feet of mine.  
For someday to not walk in my shoes  
Would be oh so wonderfully sublime.

The longing in my heart  
The pain from deep within me  
Oh how I wish these waters would wash it away  
To be rid at last, to be free

But to be without pain  
Is to be without you  
So I must ride these waters  
However rough they get and blue

Thank you my sunshine  
Thank you for the rain  
Thank you for the special moments  
When you think there's only pain

(Katie, Research Participant and Bereaved Mum)

### Declaration

The present study has three constituent parts. The first is a critical literature review, the second is a self-contained research report and the third is a critical appraisal of the research from the researcher's perspective. All parts of this research are the original work of the author, except where otherwise stated with reference to the original author(s). This thesis has been submitted in partial fulfilment of the Doctorate in Clinical Psychology at the University of Leicester and no part of this thesis has been submitted for any other degree or academic qualification.

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To the mothers who trusted me with their truest thoughts and who gave me their time despite the most demanding circumstances and to their children who sat patiently by, watching over them. To Ray, and my band, for rescuing me and for bringing music to my research. To my friends Anwen, Jo, Biswadeep, Claire and Lorraine who were always there to mop up my research tribulations...and all the rest. To my supervisors, Marilyn, Mike, Dan and Georgina, for their reassurance and guidance throughout. To my dad for believing I would succeed. To Chris for doing everything and for understanding these past 12 months. And to my most loved Grandma for her unconditional acceptance..

I am also extremely thankful to all the hospice staff who gave up their time for me, inspiring me throughout the journey, and to my cohort for being with me all the way.

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## Thesis Abstract

This thesis investigates the experiences of families caring for children with life-limiting and life-threatening conditions who are accessing paediatric palliative care (PPC) services. The research has three constituent parts: a Self-contained Literature Review, a Research Report and a Critical Appraisal.

### *Self-Contained Literature Review*

This review considers the quantitative literature around factors influencing access to PPC services by families caring for a child with life-limiting or life-threatening diagnoses. The results indicate that a number of factors influence access to PPC. Examples include: ethnicity of the referring clinician and family; malignancy of the diagnosis; child's prognosis; child's age; available resources; training and experience of staff and; family's socioeconomic status. The clinical implications of the results are explored.

### *Research Report*

The research report investigates the experiences of mothers accessing children's hospices in the care of their life-limited or life-threatened child through an interpretative phenomenological analysis of data provided in eight reflective diaries and six corresponding interviews. Four superordinate themes were identified: "Must get my Superwoman cape on"; Attachment and Child Development; A "Rollercoaster" of Emotion and; Transitioning Communities. These themes demonstrated the layers of responsibility participants took on. While hospice services were considered to be helpful in preventing stress and burnout amongst participants, their allocation of resources was insufficient to meet the complex physical and emotional needs of participants and their children. The clinical and research implications of the results are discussed.

### *Critical Appraisal*

The Critical Appraisal presents some of the researcher's reflections on the research process. The design and development of the research, its limitations and some of the lessons that were learned about conducting future research are presented.

Critical Literature Review

Factors Influencing Access to Paediatric Palliative Care by Families Caring for Children  
With Life-Limiting and Life-Threatening Conditions:

A Critical Literature Review.

Submitted to the University of Leicester in partial fulfilment of the  
Doctorate in Clinical Psychology

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## Literature Review Abstract

### *Aims*

Families caring for children with life-limiting and life-threatening conditions are at heightened risk of burnout and complex grief reactions. Access to paediatric palliative care (PPC) services to support them serves a supportive function in helping families manage their child's needs. Access remains a contentious issue with many obstacles preventing families from benefitting from these services. The current review aims to examine the literature around access to PPC services for families caring for children with life-limiting and life-threatening conditions.

### *Method*

Relevant articles were accessed through searching eight databases. Methodological rigour was assessed to ensure the quality of the research was sufficient to inform conclusions drawn from their findings. Eleven articles exploring characteristics influencing access to PPC were selected for inclusion.

### *Results*

Results showed that a number of factors negatively influenced families' access to PPC. These included: where families or referring clinicians were from an ethnic minority background; having non-malignant diagnoses; having no end-of-life prognosis; communication difficulties; child's younger age; resource constraints; lack of formal PPC staff training; more professional experience amongst trained staff and; families with a higher socioeconomic status.

### *Conclusion*

The current review concluded that there is a perception of PPC as being directly associated with death and dying. While supporting the end of a child's life, PPC services also support quality of life, evidenced by their established transitions pathway to adult PC services. Through training, a more consistent presence within universal services and more present and established care pathways, PPC may positively influence the public perception and become increasingly accessible to clinicians and families.

*Keywords:* paediatric palliative care, life-limited; life-threatened; access; barrier; child; family; paediatric, hospice.

*Target Journal:* Journal of Palliative Care

## 1. Introduction

There is an increasing international demand for paediatric palliative care (PPC) services due to the rapidly rising prevalence of children recognised as having life-limiting and life-threatening conditions. It has been suggested that between 2000 and 2010, the prevalence of life-limiting illness in the United Kingdom (UK) increased from an estimated 25 to 32 children per 10,000 population with at least 23,500, and up to double this number of children, requiring access to PPC in the UK each year (ACT 2009; Fraser et al., 2012; Mellor et al., 2012). As this group is extremely heterogeneous, definition and quantification is challenging, yet it is thought that far more children are born with conditions that may qualify for support from PPC than the population who access it (Goldman et al., 2012; Fraser et al., 2012). Despite this, currently available resources cannot sufficiently meet the needs of the underrepresented population accessing these services.

Across the UK available services are disparate, demonstrating an inequitable distribution of services to areas with a limited PPC resource (Hunt et al., 2013). The first strand of the recent ‘Big Study’ released by Together for Short Lives (TfSL) (Hunt et al., 2013) investigated the prevalence of need in PPC services across one geographical region of the UK. More densely populated areas<sup>1</sup> demonstrated higher levels of unmet PPC need. This study brought further attention to the lack of available services for families and identified the requirement for more accessible services from the point of life-limiting diagnosis and thereafter.

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<sup>1</sup> The term ‘densely populated’ was characterised by higher rates of children with life-limiting and life-threatening conditions per 10,000 children.

## *1.1 Terms and Definitions*

### *1.1.1 Life-limiting and Life-threatening Conditions*

For the purposes of the current review, the term ‘life-limiting’ is used to describe children diagnosed with a condition for which there is no reasonable hope for curative treatment and from which they are likely to die. The term ‘life-threatening’ is applicable to children with conditions that may be curable but may also fail to respond to treatment. Children falling within these definitions are entitled to access PPC services.

### *1.1.2 Paediatric Palliative Care*

A range of different services have been established within PPC to support the needs of incurably ill children and their families by offering compassionate support from the point of diagnosis to after death. An exemplary model of PPC encompasses well-coordinated physical, emotional, spiritual and social elements to care; promoting quality of life on a needs-led, individualised basis. It should be planned in collaboration with the child and their family, offering support managing distressing symptoms and providing respite and care through to death and during bereavement (Chambers et al., 2009).

There are four stages within the trajectory of illness: diagnosis; care and support; end-of-life care; and bereavement support. Services within a PPC framework typically include: care coordination; symptom management; psychological, spiritual and social support; financial and practical help; short-break care; end-of-life support; and bereavement care. These services are usually offered to infants, children, their families and other significant people within their network from birth to adulthood and during transition to adult palliative care (APC) (Chambers et al., 2009). It is currently recognised that PPC should be offered as early into a child’s diagnosis as possible.



## *1.2 Paediatric Palliative Care Guidance*

In 2004, ACT, the leading children's PPC charity, published the 'Integrated Multi-Agency Care Pathway for Children with Life-Threatening and Life-Limiting Conditions' (Elston et al, 2004) establishing standardised guidelines for accessing and providing children's PPC. In 2007 this publication was supplemented by two additional documents to guide neonatal care and transitions to APC services. These movements towards developing consistency, reliability and cohesiveness in PPC have continued in the UK. In 2012, TfSL, previously ACT, released a Charter encompassing ten statements relating to the care that children, and their families and friends, should expect from PPC. It iterates the expectation that all families with children who have been diagnosed with life-limiting conditions are entitled to access individualised packages of care.

## *1.3 Implications for Accessing Paediatric Palliative Care*

Family members who are unprepared and insufficiently supported in their caregiver role are significantly more likely to experience anxiety, depression and low levels of confidence when coping in this role (Lindstrom & Melnyk, 2012). These factors are associated with the development of complex grief reactions from the anticipatory grief stages to after the death of their child, thus demonstrating a need for access to an optimal level of PPC to ensure the best outcome for parents. Proactive and preventative approaches to care are of great importance to avoid unnecessary symptoms of psychological distress to children and families. Responding early relieves the resource pressures that PPC may later face and saves longer-term cost implications for wider services (Pfund & Fowler-Kerry, 2010).

While the value of PPC has become more widely recognised and its use has increased, access remains a central issue. The National Hospice and Palliative Care Organisation (2001) estimate that up to 90 percent of children who may benefit from these services never receive them. Bradford et al. (2012) suggest that there can be a 'refusal to acknowledge the need for

palliative care’ by clinicians as ‘it’s a very difficult conversation to have with parents’ due to a ‘fear of knowing what to say’. While PPC may be dedicated to facilitating access, clinicians from universal healthcare services may be reluctant to take part in these conversations due to fear of the emotions evoked within themselves and the families they are working with.

In the UK, PPC has begun to establish a Care Pathway Approach to overcome some of these challenges. Pathways are usually formed through specialist, ongoing, local PPC consultation with appropriate services that may benefit from a consistent PPC presence, such as neonatal and oncology wards. Bradford et al. (2012) allude to a number of reasons why access to PPC may continue to be complex and emphasise the risks families face when they are insufficiently supported.

#### *1.4 Aims*

The current review aims to examine the evidence relating to families’ access to PPC when they have a child with a life-limiting<sup>2</sup> condition. It intends to identify the barriers and facilitators to access in the hope to inform services who refer to and offer PPC.

## **2. Method**

### *2.1 Literature Searching*

A systematic review of the literature relating to access to paediatric palliative care (PPC) services was conducted using eight databases: *PsycInfo*; *Medline*; *AMED*; *EMBASE*; *BNI*; *CINAHL*; *Web of Knowledge* and; ‘*Synopsis*’ (Together for Short Lives). A wide range of search terms were used to capture all applicable literature. Search terms were categorised into three lists of synonyms encompassing related and truncated terminology. Each database was searched for articles containing any combination of terms from each list using Boolean logical operators (Appendix A).

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<sup>2</sup> For the purposes of the current review, the term ‘life-limited’ will be used to encompass all children who qualify to access PPC.

Appendix B offers a flowchart of the literature searching process and demonstrates that a total of 7611 articles were initially returned. The titles of these articles were screened for their relevance and where the title indicated that the article may address issues of access to PPC, it was deemed suitable to pass this initial screening. If there was any uncertainty as to whether an article directly addressed access to PPC, the abstract was retrieved for consideration; this resulted in 147 potentially relevant articles. After removing duplicates, 98 articles remained, abstracts of which were then reviewed against the initial screening criteria as set out in Section 2.2.1. Forty-seven articles met the initial criteria for inclusion in the current review and were retrieved.

A secondary search of reference lists from the retrieved articles was conducted and a further four articles were located; as they met initial screening criteria these were also included. To ensure any relevant and unpublished literature was considered for applicability, contact with Together for Short Lives (TfSL) was made. Following discussion with the Development Director and contact with a specialist working in the area of PPC, no applicable unpublished literature was identified, although the reviewer's attention was drawn to one recent publication (Hunt et al., 2013). The internet search engine, Google, was also used to identify articles that may not have been captured in previous searches; one further article was located and included. The final inclusion criteria (Section 2.2.3.) were applied to a more in-depth review of the 52 shortlisted articles; 12 articles met these criteria.

## *2.2 Inclusion Criteria*

### *2.2.1 Initial Inclusion Criteria*

Articles must have been published in English between 2000 and 2013<sup>3</sup>; these parameters were felt to adequately capture the recent evolution of PPC. Only literature relating to the

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<sup>3</sup> Literature searching was conducted between July and August of 2013.

paediatric population was included due to the stark differences between adult and paediatric PC. The definition of ‘child’ was considered broadly to capture an international perspective; it was recognised that there is no commonly held, international consensus on the cut-off age for a child.

### *2.2.2 Initial Exclusion Criteria*

Articles were excluded if they solely considered the experiences of those already receiving PPC without consideration of the experience of accessibility. In order to focus on novel research, meta-analyses or systematic reviews would have been excluded however, no applicable reviews were found.

### *2.2.3 Final Selection Criteria*

Articles employing quantitative methods were included in the current review to ensure coherence in synthesising the results. Those articles deemed overly specific because they focused on only one function of PPC, such as respite or short-break care, were excluded as the aim was to capture a wider overview of PPC.

There has been a widely held consensus that adult and oncology populations dominate the PPC evidence base (Malcolm et al., 2008; ACT, 2009). While it is appreciated that up to 40 percent of a PPC practitioner’s caseload may be dedicated to children with cancer diagnoses, it was felt that the other 60 percent also warranted consideration (McCulloch et al., 2008). This is particularly relevant given the unique and specialist nature of paediatric conditions that, due to their rarity, may not have been included in previous disease-specific research. It was hoped that the inclusion of evidence drawing from more heterogeneous samples investigating children with a range of diagnoses would offer a representative overview of access issues. This may also ensure that literature comparing access issues between the different diagnostic categories might be captured. For example, it was

hypothesised that perhaps children falling within some diagnostic categories may access PPC more than others. Therefore, articles limited by investigating only disease-specific populations were excluded from the current review. It was appreciated that through the exclusion of this literature, some factors of relevance relating to issues of access to PPC may not have been identified.

All 12 articles were scrutinised against an appraisal tool considering their reported methodological features (Section 2.3). Those given a score of below ten were excluded to ensure only articles that reported sufficient quality were reviewed.

### *2.3 Appraising Included Articles*

The 12 shortlisted articles had cohort, case series or cross-sectional designs. The appraisal tool was designed to standardise the initial process of evaluating the methodological features reported in the articles. The tool was informed by the recommendations of relevant review literature (Fink, 2005; Aveyard, 2010) (Appendix C). Articles were assigned scores for individual items, while also achieving a total score, thus demonstrating the quality in reporting overall and within each area. All articles were scored twice, seven days apart, to ensure that scores were assigned in a consistent and standardised way. Where there was discrepancy between scores, the item was considered a third time and the median average score was settled upon. One article was excluded because it was deemed of inadequate standard for final inclusion. It should be emphasised that this appraisal tool was used to assign scores based only on the reporting of methodological features within the articles and not the overall quality of the research itself.

The Critical Appraisal Skills Programme (CASP, 2004) and STROBE (von Elm et al., 2007) were used to guide a wider appraisal of the quality of the included articles. These tools are available to guide the appraisal of studies employing a variety of different designs; the

most applicable tools were matched to the specific design of the study. While these appraisal tools could have been integrated and utilised as a scoring system, it is recognised that they have a number of weaknesses which may not lend to such an inflexible method as a numeric scoring system (Costa et al. 2013).

### 3. Results

Eleven articles remained and were included for review having met the final inclusion criteria. These were ordered alphabetically by author, summarised and assigned a final identifying number (Appendix D). Four of the studies included for review employed case series designs (1,7,8&10), six used cross-sectional designs (2,4,5,6,9&11) and one used a retrospective cohort design (3).

#### *3.1 Methodological Features*

Appendix C summarises the reported methodological features scores of articles included for review. Articles were scored out of 24 based on the quality of the information provided in the publication; higher scores indicated a better quality of reporting. Each article could score between 0 and 2 on each item: 0 represented an absence of reporting; 1, partial reporting; 2, full reporting.

Of the 11 articles included, a wide variation in methodological rigour was reported. Scores ranged from 10 to 16 with a mean of 12.7 and median of 12. There were common gaps in reporting the reliability and validity of measures used. Only article 4 discussed reliability to a moderate degree and article 1 comprehensively explored the notion of validity. A calculated effect size was also significantly underreported, with only two articles (1&8) making reference to this. In reflecting on the representativeness of the sample, no article achieved a full score and only two of the articles directly reported their hypotheses (1&8).

All 11 articles answered the questions they set out to answer and demonstrated good appreciation and exploration of the meaning of their findings. Particular detail was given to reporting the methods used and sample demographics, with all studies scoring at least partially for this; 10 out of 11 articles scored fully for reporting the demographic features of their sample. The 11 shortlisted articles were grouped according to the broad theme of each study. Five articles (1,3,7,8&10) explored the characteristics influencing access to PPC. Six articles (2,4,5,6,9,11) explored perceptions of PPC.

### *3.2 Characteristics Influencing Access to Paediatric Palliative Care*

The studies were synthesised by their respective designs. Five (1,3,7,8,10) used retrospective methods to explore the characteristics of those who had accessed PPC. Three of these studies (1,8&10) considered location of death (home, hospice or hospital) and trends in referral patterns by conducting descriptive analyses on different patient databases. Another study (7) drew from data held on a state-wide database to consider the characteristics of different hospice organisations and to determine how services were provided. Article 3 used a Paediatric Health Information System database to compare those referred and that had received PPC, with those who had not. The longitudinal nature of these retrospective methods offers an insight over an extended period thereby capturing the changing landscape of PPC. However, when considering the recent and rapid evolution of PPC, retrospective data could not capture the current climate despite being able to indicate a direction of evolution. It is noteworthy that the databases from which data were drawn contained information to varying degrees of validity and representation.

#### *3.2.1 Location of Death*

Articles exploring location of death were deemed relevant to the current review because of the widely held consensus reflected in the literature that most often families will prefer their children's place of death to be at home, followed by hospice, and least of all hospital

(Bluebond-Langner et al., 2013). While PPC offers a number of services to families, facilitating the planning of end-of-life care is one of its more specialist functions (Hynson et al., 2003). If a family's end-of-life plan is not initiated or realised, the factors influencing why their plan was unsuccessful requires addressing by PPC services. Research investigating the barriers and enablers to family preference in location of death may identify why the PPC services required were not accessed or successful in achieving this task.

Chang et al. (2013) (Article 1) investigated characteristics that influenced the location of death (home, hospice or hospital) for children with life-limiting illness using a case series design considering the demographic profiles of 494 children from across New Zealand between 2006 and 2009. Their findings indicated that children from ethnic minority backgrounds were more likely to die in hospital than Caucasian children who were likely to die at home or in a hospice, as were infants when compared with older children. They found that referral to PPC meant children were less likely to die in hospital. The central finding was that children with a cancer diagnosis were significantly more likely to die out of hospital than those with non-malignant disease trajectories.

Siden et al. (2008) (Article 8) used a case series design and considered location of death from PPC sites in the United Kingdom (UK) (n=318), Australia (n=233) and Canada (n=152) between 2000 and 2006. They found that diagnosis significantly influenced the location of a child's death. Cancer, metabolic and biochemical diagnoses corresponded to dying in a paediatric hospice or at home. There were also differences between the three countries: in Canada children were most likely to die in a hospice; in the UK children were equally likely to die at home or in hospital and; in Australia they were most likely to die at home. Overall, children were equally likely to die in hospital, hospice or at home.



Vadeboncouer et al. (2010) (Article 10) investigated the location of death and trends in referral using a case series design considering 341 children referred between 1999 and 2007 in one PPC programme in Canada; of these, 189 children died during the study period. Most children died in hospital, second most commonly, children died at home, and least of all, in a hospice. They found that hospital and home deaths increased where PPC services were involved in the care of children, although hospital deaths still dominated. The service under consideration was a developing service which grew significantly during the study. All disciplines referred to PPC, particularly neurology and neonatal intensive care. Referrals also increased across all diagnostic categories indicating that the more present and established the PPC service, the more likely it will be utilised.

The narrative synthesis of these three articles supports the notion that ethnicity, younger age, absence of referral to PPC and non-malignant diagnoses, increase the likelihood that children with life-limiting conditions will die in hospital. Previous evidence suggests that most families prefer their children to die at home or in a hospice (Vickers et al., 2007; Bluebond-Langner et al., 2013). Therefore, factors associated with the increased likelihood of death in hospital indicate areas for further consideration by PPC services so as to increase access opportunities, as well as more effective service provision. Paediatric PC is designed to facilitate end-of-life care decisions and raise awareness of the choices families have available to them. These studies demonstrate the effectiveness of PPC access in planning for place of death and draw attention to underrepresented groups demonstrating the need for further research to guide understanding of why these groups are underrepresented.

These studies are helpful in offering an international profile of the similarities and differences in the location of death of children across five countries. In recognising the cultural differences and geographical compositions of these respective countries, it is possible to deduce elements that may influence access to PPC. For example, more children may die at

home in Australia because of the rural nature of the country and distance between home and hospice. The recent 'Big Study' (Hunt et al., 2013) supports this hypothesis by confirming that services in the UK are less available to families living in rural and remote areas.

Article 10's findings conflicted with the findings from article 8 which intimated that Canadian children were more likely to die in a paediatric hospice. However, it is recognised that the two PPC programmes were in geographically different locations (Eastern Ontario: Vancouver) serving different populations and offering a different range of services. There was also diversity in the representiveness and generalisability of the samples within these studies. For example, article 10 considered only one PPC programme when compared to article 1 which drew on a population from across New Zealand and had a larger sample size which was likely to be more powerful.

### *3.2.2 Features Enabling Paediatric Palliative Care Provision*

Keele et al. (2013) (Article 3) used a retrospective cohort design to compare children who received (n=919) and did not receive (n=23,423) PPC across 40 children's hospitals between 2001 and 2011 in America. Factors influencing whether PPC was accessed included: older age; ethnicity; private insurance and; diagnostic category. Older children were more likely to receive PPC than younger children; white children were more likely to receive PPC than African-American children; families with private insurance were more likely to receive PPC and; those with central nervous system and malignant diagnoses were more likely to access PPC services. Where PPC was accessed, the study found that children received fewer invasive procedures such as medications, ventilation and parenteral nutrition. There were also decreased numbers of intensive care admissions for those in receipt of PPC and less likelihood of dying in hospital. The authors indicated that less invasive treatment is preferable for life-limited children because such treatment impacts on their quality of life. Therefore, access to PPC was felt a more appropriate and beneficial pathway.

Lindley et al. (2013) (Article 7) used a case series design to consider features associated with the provision of hospice care for children from an organisational perspective. By investigating 311 hospice organisations from across America they found that hospices were more likely to offer paediatric services where they had a professional membership to a relevant affiliated body. Hospices categorised as ‘small’ or ‘medium’ were less likely to provide a PPC element, and where there had been competition with other hospice organisations in the previous year, the chances of offering PPC were reduced.

In line with articles 1, 8 and 10 which focused on location of death, article 3 added to the evidence indicating that some factors influencing PPC access include: ethnicity; younger age and; non-malignant diagnoses. It also confirmed that dying out of hospital and a reduction in time spent in hospital was associated with access to PPC. Article 8 introduced the concept that important elements of a PPC pathway, such as a paediatric hospice resource, may not have been accessible to families because of the financial and organisational implications of offering care to children. Only larger-scale hospice organisations without competition were able to offer a paediatric facility. This corresponded to findings from article 10 which suggested that when the investigated PPC programme was in its earlier stages of development, there were fewer referrals to the service. The referral rate grew as the resource developed. Smaller, less established services risk being underutilised due to a deficit of referrals; this, in turn, may prevent PPC services from developing and result in an inability to sustain the resources required by families.

Both articles 3 and 7 offer further weight to the narrative synthesis and draw attention to practices in America. They are both large-scale studies and likely to reflect powerful findings from a national sample which have not been limited to single PPC organisations. While useful to inform current UK practices, the generalisability of some of the findings in influencing clinical practice in the UK might be limited due to the cultural disparity in the

design of these services. For example, the model of hospice provision in the UK is such that paediatric and adult hospices are usually run separately; in the USA hospice care is more integrated where organisations may encompass a paediatric and adult function. Attention is also drawn to the culture of private medical insurance in America which is more dominant than in the UK due to the established National Health Service. Whether private health insurance or affiliation to a professional body would influence access to PPC services in the UK is unclear.

### *3.3 Perceptions of Access to Palliative Care*

Six articles (2,4,5,6,9&11) considered perceptions and attitudes towards access to PPC from a range of healthcare providers' and organisational perspectives. Two articles (2&11) focused on the perceived barriers to PPC and gaps in services available. Four articles (4,5,6&9) focused on professionals' referral preferences and attitudes towards PPC. All six utilised survey methods to consider the views of participants and to collect demographic data but did not report on the validity of the measures used. Four studies (2,6,9&11) reported either conducting a pilot of the measures, or submitting the measures for peer review before utilising them in the research thus indicating that issues of validity and reliability had been considered.

#### *3.3.1 Perceived Barriers and Gaps*

Two studies (2&11) focused on the barriers to PPC for children as perceived by paediatric healthcare providers and parents of families accessing care for their children. Both considered the views of a different sample, lending well to a holistic understanding of the current need of the clinician, the family and the wider healthcare system.

Davies et al. (2008) (Article 2) used a cross-sectional design to consider the barriers to PPC in one American, academic children's hospital as 240 healthcare professionals would

perceive them; 117 of these were nurses and 81 were physicians. Four of 26 possible recurring barriers were most commonly identified. Families' inability to acknowledge the incurable nature of their child's condition was a central factor. It was felt this was because families preferred to retain hope that curative treatment would be successful rather than access PPC which was felt to be indicative of an end-of-life prognosis. Uncertainty of prognosis by clinicians was also a central barrier, suggesting that clinicians held the perception that PPC services could only be accessed after a palliative prognosis had been determined. Language and communication barriers were identified as a significant hindrance to meeting family need. Finally, constraints on staff resources were highlighted as key factors influencing the receipt of PPC; referrers' resources were felt to be limited, as were the resources of PPC services being referred to due to funding limitations. Another eight barriers were commonly identified by respondents and these were associated with communication problems and difficulties with education about pain management and PPC; of particular note was the lack of a PPC consultation team for staff to access specialist advice.

Nurses and physicians differed in the emphasis they placed on factors within the four key established barriers; there were also differences between intensive-care and non-intensive care nurses' views. Furthermore, the authors identified that established barriers were different to those arising from the literature relating to adult PC with significantly less emphasis on fears of legal action, hastening death and addiction to medication in PPC.

Verela et al. (2012) (Article 11) focused on barriers to paediatric hospice care in North Carolina from an organisational perspective (N=61). They compared 26 hospices that were providing PPC with 35 that were not and found that hospices serving children perceived barriers to PPC services differently to those who did not. Those serving children felt the main barriers included: lack of paediatric referrals; families preferring to continue curative therapies; the highly complex presentations of children; lack of trained staff; lack of

paediatric consultation; lack of certainty about prognosis and; language barriers. Hospices not serving children perceived barriers to PPC to be due to: a lack of trained specialist staff; inconsistent plan of care between paediatrician and hospice; lack of paediatric pharmacy services and; lack of available specialist consultation.

Articles 2 and 11 reiterated several factors that influenced access to PPC and were identified in the other studies. Recurring themes included: language and communication difficulties; lack of referrals; families' lack of readiness to accept PPC; resource constraints or inappropriate availability of resources and; uncertainty of prognosis. The lack of insight into the services PPC offered was emphasised, demonstrating the need for universal and PPC services to communicate more effectively and establish a more systematic Care Pathway Approach. The studies show that staff were aware of their need for further insight into PPC through highlighting the need for specialist consultation services to inform appropriate referral pathways.

Uncertain prognosis is another recurring theme in the current review, suggesting that medical staff may have been reluctant to communicate a palliative prognosis to families. This may be because of uncertainty but also because the conversation is difficult to have with families; PPC intimates a loss of hope (Bradford et. al., 2012).

Article 2 focused on one site, thereby limiting the generalisability of its findings reinforced by its low response rate of 34 percent which might be interpreted with caution. A strength of the study was that it considered a cross-section of opinions from different professionals and offered a multidisciplinary perspective. Article 11 cast its net wider to incorporate the views of several organisations yet focused only on hospice care rather than general PPC services; the utility of this is questionable as a hospice perspective was likely to exclude the broader context of PPC.

### *3.3.2 Referral Practices and Attitudes*

Four studies considered referral practices and attitudes to PPC (4,5,6&9). Two of these considered the perceptions of nurses (4&5) and two focused on the views of paediatricians (6&9).

Knapp et al. (2009a) (Article 4) used cross-sectional methods to investigate the effect of a Florida-based PPC programme in relation to the referral practices of 279 nurses; 141 worked in a PPC unit and 138 worked in a unit without the presence of a PPC resource. They found few differences between nurses employed in a PPC unit and those who were not when considering overall referral rates. However, those employed in a unit were between 3.7 and 10.4 times more likely to refer prior to end-of-life diagnosis. Diagnosis was an influential factor in referral practices; fewer nurses would refer for diabetes while all nurses would refer for cancer. This is likely to be because diabetes was not perceived by all PPC services to be a life-limiting condition. Nurses from ethnic minorities were less likely to refer to PPC for certain diagnoses and those with more formal training were likely to refer earlier.

Knapp et al. (2011) (Article 5) published an additional article, drawn from the findings from the investigation that informed article 4. This second publication considered the attitudes of nurses towards PPC. They found that nurses from PPC program sites had more positive attitudinal scores towards PPC and hospice. There were also higher levels of positivity in those who had received formal training in relation to PPC.

Knapp et al. (2009b) (Article 6) investigated paediatricians' perceptions of referrals to PPC using cross-sectional methods and drawing from a sample of 303 paediatricians from across Florida and California. They found that paediatricians were more likely to refer to PPC prior to end-of-life if the paediatrician was from an academic setting or if they had more 'Medicaid' patients on their caseload. Medicaid is an initiative for patients receiving state

support due to their low-income status. Hispanic paediatricians, those who were more experienced and those based in a hospital setting were less likely to refer prior to end-of-life. This seems counter-intuitive given that those with more professional experience and those based within hospital settings will have most likely had more exposure and therefore increased awareness of the services offered within PPC.

Knapp et al. (2009c) (Article 9) published a second article from the findings of their study (6) focusing on the perceptions of and preferred timing for PPC. Paediatricians were divided in the way they defined PPC, giving the definition used for hospice care as opposed to a broader definition for wider PPC services; others did not know how to define it. Less than half the sample had referred to PPC and less than one third were aware of locally available PPC services. There was no consensus as to timing of referral to PPC and no relationship between how they would define PPC and whether they had referred to it. This suggested that having an understanding of the service did not correlate with its increased use.

Together, these four articles offer an insight into what may affect nurse and paediatrician referrals to PPC. They support the notion that staff characteristics may be influential in considering accessibility to PPC, with some characteristics mirroring those that serve as barriers to the patient population. For example, membership of ethnic minority groups reduced the chances of both nurses and paediatricians referring patients to PPC, as did less training and education in PPC. The notion that medical professionals are confused by the definition of PPC is commonly recognised (Jones, 2011). There were some interesting differences between nurses and paediatricians reflected in these studies as nurses' referral practices and attitudes adopted a more positive approach when they had more experience and this corresponds to earlier referrals. Conversely, paediatricians were found to refer later and less often when they were more experienced in their profession or based in hospital settings. The culture and role of these different professions could be influential when comparing them.



Potentially paediatricians develop confidence and feel less need for input from specialist services, while nurses may embrace a more universal model of healthcare, accepting support and consultation from specialist services.

The strengths of these four articles are also embedded in their weaknesses. They were formed from two studies suggesting they conducted a thorough and comprehensive investigation of their respective samples. However, this also provided a smaller body of objective evidence from independent sources. The articles were predominantly published by the same authors which increases the possibility of reporter bias. All were American studies and therefore the main body of the current review was influenced by an American PPC model (n=8).

## 4. Discussion

### *4.1 Summary of Results*

The current review explored factors influencing how families caring for children with life-limiting and life-threatening conditions accessed paediatric palliative care (PPC) services. As there was an absence of literature to directly inform this question, the review consists of articles considering two main themes: the characteristics of those accessing PPC and perceptions of PPC. Within these two themes, four subordinate themes were reviewed, including: location of death; features enabling PPC access; perceived barriers to PPC and; referral practices and attitudes.

There were nine key factors that prevented families from accessing PPC services: (1) Families and referring staff from ethnic minorities were less likely to initiate access to PPC before an end-of-life prognosis was formally established; (2) communication difficulties, such as language barriers, or communication between different services, was not well managed and sometimes care pathways were either absent or ineffective; (3) younger age;

neonates and younger children were less likely to access PPC; (4) diagnoses that were not malignant, particularly non-cancer diagnoses, were referred later and resulted in an increased likelihood of dying in hospital; (5) country of origin demonstrated how services were set-up differently in different countries. Children with PPC needs were equally as likely to die in hospital or at home if they lived in the United Kingdom (UK); (6) resource constraints such as staff shortages, the small-scale of PPC organisations, lack of staff formal education and training in PPC and, an absence of specialist consultation; (7) referrals were directly linked to the presence of a PPC resource. Referrals were also influenced by staff characteristics and profession as more professional experience and less training in PPC correlated with fewer referrals; (8) without an established end-of-life prognosis children waited longer for a referral to PPC; (9) lower-income families or families from areas of higher deprivation were more likely to be referred.

The literature presents the hypothesis that there is a great deal of inequality in factors enabling access to PPC services. A family is more likely to access PPC if they live in a deprived area and their child is diagnosed with cancer where an end-of-life prognosis has been determined and communicated. They might be Caucasian and under the care of a Caucasian nurse who speaks the same language and has been formally trained in PPC. It will also be important that there is a local (to home and hospital), well-established and resourced PPC programme offering specialist consultation and having a well-communicated care pathway between PPC and universal services.

#### *4.2 Outcome of the Review*

The current review attempted to address the absence of literature identifying factors influencing families' access to PPC. Through focusing on characteristics of those accessing PPC and their perceptions of these services, this review offers useful evidence for PPC services to consider when establishing care pathways in the future. By integrating a range of

articles covering a number of themes, it has reduced the paucity of available evidence and provided an international insight into different elements of PPC access and currently established pathways.

#### *4.3 Limitations*

There are a number of identified limitations within the current review largely associated with the international nature of the articles included. In the first instance, it is recognised that models of PPC differ significantly, both within and between countries. These differences are particularly apparent when comparing America and the UK because of their differing commercially driven versus publically-funded health services. However, both America, the UK and a number of other countries with developed PPC services, including Australia and Canada, rely heavily on philanthropic funding to support their palliative care services, particularly in relation to hospice care. Also worthy of consideration is the current evolution of the National Health Service (NHS) within the UK which is progressing rapidly towards a business model of care provision, inviting competitive tender from commercialised industry (Ham, 2012). While the two models of PPC may currently continue to operate in a number of different ways, discrimination between them is becoming less apparent. Therefore, while there are several differences, there are also a number of similarities; most in common might be their resource challenges. However, as the current review drew mainly from studies recruiting from non-UK based sites, its generalisability within the UK should be considered with caution.

Due to the nature of the current review forming part of a portfolio of coursework contributing towards the reviewer's Doctorate in Clinical Psychology, it was recommended by the university that a maximum of 12 articles could realistically be included within a useful literature review of this scope. Had this not have been a limitation, a larger selection of articles might have offered a more representative overview of the literature. Within this,

alternative inclusion criteria may have generated different articles and been more generalisable to a different population such as the UK. A different method for shortlisting might have been based solely on an appraisal of the articles' reported methodological features; a quality appraisal.

Three of the articles selected for review considered location of death and referral to PPC. While these articles indicated where barriers to PPC access may lie, the location of a life-limited child's death may also be influenced by a number of other variables that remain outside the control of the available PPC resource. For example, the reason for a child's hospital admission may not have been initially recognised as an end-of-life incident. Many children with life-limiting conditions are admitted to hospital with chest infections each year, yet the effectiveness of their treatment cannot always be predicted and they may die without sufficient warning of this; thus PPC services may not always have the opportunity to support the implementation of a family's end-of-life care plan. In accordance with this, the unreported influence of extraneous variables that were unaccounted for may also have impacted on other areas identified for scrutiny within the current review such as staff referral practices and attitudes towards PPC.

Synthesising the articles was complicated when considering their different designs and the diversity within the areas of PPC they focused on. Common limitations were identified when quality appraising the reported methodological features of the articles, indicating that research in this area may be yet to identify itself as an established entity. For example, reliability and validity of survey instruments and databases used were rarely reported, suggesting that much of the literature may be formed from methods more oriented towards practice-based-evidence designs (Malcolm et al., 2008; McCulloch et al., 2008). This is understandable given the sensitivity of the research area which will no doubt be influenced by design limitations, ethical constraints and population biases (Stroebe et al., 2003).

However, a combination of evidence emerging from practice, and initially designed to inform practice might have been more useful to the current review (Barkham et al. 2001).

There is a distinct lack of reliable evidence in the area of PPC which is confirmed by an over-dependence on adult and oncology evidence to inform practice (Malcolm et al., 2008; ACT, 2009). The samples used in all 11 articles included in the current review drew from the views of medical and healthcare professionals which highlights the lack of quantitative research directly reflecting the views of families. Complex ethical and methodological issues such as the sensitivity of the subject area, or a previous absence of an adequate PPC service to form the subject matter for investigation, may make formalised research in this area with families difficult to achieve (Stroebe et al., 2003; Tomlinson et.al. 2007).

Review literature (Fink, 2005; Aveyard, 2010) was used to inform the assessment of methodological features (Appendix C) and adapted accordingly for the purposes of this review. It is recognised that this is not a validated assessment tool and considered only the reported methodological features of the articles. In drawing from the Critical Appraisal Skills Programme tools (CASP, 2004) and STROBE (von Elm et al., 2007), in combination with the assessment of methodological features tool to inform the appraisal of the studies, a comprehensive assessment of the quality of the articles should have been achieved.

#### *4.4 Future Research*

The current review has demonstrated some of the numerous difficulties for families in establishing access to PPC services. Practice-based evidence and research conducted using only a professional perspective is not adequate and further investigation using systematic research methods is required. Adopting a user-led strategy where service users are included in the early design and set-up stages of research is likely to enable better access to PPC populations. Such service-user-inclusive strategies might enable the development of a rapport

with families at the early design stage thus supporting their participation in the research and enabling more user-led as opposed to staff-led studies. In line with this, issues such as cultural inequality preventing ethnic minority groups from accessing PPC might be more easily investigated; improved cultural sensitivity may enable issues of diversity to be more usefully investigated (Thienprayoon et al., 2013).

Larger-scale, multi-centre, mixed-methods approaches using validated measures would offer a more reliable contribution to the evidence base. While an international perspective is useful to inform the current review, it is recognised that practices of PPC within the UK are different. Further UK research would lend to the body of available evidence which would be especially useful given the rapidly evolving nature of these services. It might also be useful to review and research individual services within the PPC umbrella as this may generate constructive recommendations for improved access to services.

These results have raised a number of questions that might be addressed through further research and the review of available literature. A particular emphasis should be placed on developing more UK-based research to answer questions such as:

1. What is the impact of cultural diversity when considering access to PPC services?
2. What are the differences in outcomes for families who access and do not access PPC services?

#### *4.5 Clinical Implications*

The findings described in the current review might influence PPC services to reduce the inequalities identified in accessing their services. As discussed, the reviewed literature indicated that families from ethnic minority backgrounds, who are of higher economic status, who have no formal end-of-life prognosis, have a non-malignant condition or have younger children are likely to wait longer before access to PPC is facilitated. It will be important for

PPC services to recognise where these inequalities lie in order for them to better enable these populations. Engaging service users from diverse backgrounds is part of the Department of Health agenda (2010) and might be achieved in a number of ways that have been clearly identified in the findings of articles included in the current review.

Training and education of non-PPC staff, complemented by a consistent presence from specialist PPC staff for consultation, will be important. The messages conveyed through such training might be that referral early in the process of diagnosis is appropriate even without an end-of-life prognosis as PPC services can offer a valuable contribution at the early stages as well as at the end-of-life. Establishing agreed care pathways with universal services and formulating outreach strategies will be important ways to enable families' access to PPC by raising awareness of the availability of these specialist services.

#### *4.6 Conclusions*

A number of factors relating to equality and diversity have been shown to influence families' access to PPC services in the current review. Perhaps the central theme emerging from the synthesis of these factors relates to the meaning and public perception of PPC as one of death and dying. Through training and a more consistent presence, PPC professionals might be able to engage families and professionals by developing the culture of PPC from its current reputation to one intended to celebrate and facilitate quality of life. PPC offers a range of extensive services which are quite different from an adult palliative care model (Malcolm et al., 2008); through embedding a more accurate perception of its services, it might become a more feasible option for families and professionals to conceptualise. This may also enable professionals to feel more skilled in having difficult conversations with families about their child's condition.

A number of limitations have been identified with the current review, most relating to its generaliseability across the UK given the inclusion of American articles. Of particular consideration is the issue relating to the separateness of PPC services from acute hospital and other paediatric services. If there was less of a demarcation, progression through to PPC could be a more seamless developmental pathway without its present stigma and ‘death sentence’. However, this presents serious challenges for the American healthcare system which is even more segmented than that of the UK’s due to commercial competitive interest. Nevertheless, this is the route the present NHS may be moving towards.



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## Research Report

Mothers Experiences of Hospice in the Care of their Child: An Interpretive  
Phenomenological Analysis of Reflective Diaries and Interviews.

Word Count of Research Report (Excluding Tables, Figures and Appendices):

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## Research Report Abstract

### *Aims*

There is a paucity of literature considering the experiences of parents accessing children's hospice services in the care of their life-limited and life-threatened child. The current research aimed to explore parent experiences in the hope to enhance the limited evidence base and to contribute to the development of a measure of outcome for use by children's hospice services.

### *Method*

A longitudinal, combined qualitative method was used. Eight participants recruited from across two sites in one hospice organisation, completed weekly reflective diary entries over a 12-week period. Six of these participants elected to take part in semi-structured interviews at the end of their participation. An Interpretive Phenomenological Analysis method considered how participants made meaning from their experiences. This process was validated using the interview data.

### *Results*

Four superordinate themes were identified: "Must get my Superwoman cape on"; Attachment and Child Development; A "Rollercoaster" of Emotion and; Transitioning Communities.

### *Conclusions*

These themes demonstrate the many layers of responsibility that mothers of children with life-limited children accessing hospice services assume. It is recognised that hospice services are greatly helpful in preventing burnout and enabling resilience within families, yet the availability and allocation of these services is lacking. Clinical and research implications of these findings are discussed.

## 1. Introduction

### *1.1 Background and Context*

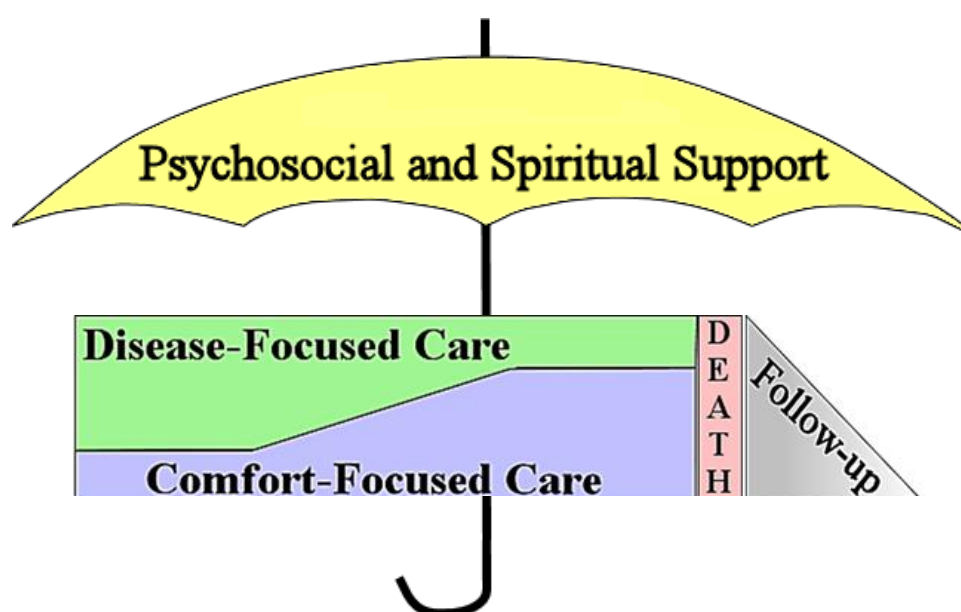
The political climate relating to life-limiting and life-threatening illness in children has been a topic of controversy across the world in recent years (Pfund & Fowler-Kerry, 2010). This year Belgium's parliament legalised child euthanasia, with parental consent, for terminally ill children 'suffering unbearable pain' (Presley, 2014). As the first ruling of its kind, this law highlights children's rights to live and die in dignity and reminds us of the consequences for parents living in the United Kingdom (UK), a country offering them limited choices to act in the best interests of their child. The National Health Service (NHS) is ill-equipped to meet the needs of families with children with such complex healthcare needs and relies heavily on parents, carers and the voluntary sector to coordinate the specialist care of these children (Thornes, 1990). For parents, this role entails providing life-sustaining care for their child who may be in acute chronic pain. In the absence of choices, coping in this role may be achieved through dedication to improving the quality of the life their child is destined to lead. This context begs the question: How do parents manage the complicated emotional consequences of holding this role within a culture that limits freedom of choice?

Each year at least 23,500 children, or up to double this number are diagnosed with life-limiting or life-threatening conditions; over half of these are likely to require support from paediatric palliative care (PPC) (Chambers et al., 2009; Fraser, 2012). Family members and carers supporting these children amount to between 80,000 and 100, 000 people. In the UK, these families require support from a number of universal, core and specialist hospital-based and community services during the trajectory of their child's illness.

## 1.2 Paediatric Palliative Care

There are four stages within the evolving model of PPC: diagnosis and treatment; care and support; end-of-life care; and bereavement support. Services within the PPC framework typically include: care coordination; symptom management; psychosocial and spiritual support; financial and practical help; short-break care; end-of-life support; and bereavement care. These services are offered to infants, children and their families from birth to adulthood and during transition to adult palliative care.

Figure 1: Evolving Model of Palliative Care



The term 'life-limiting' is used to describe children diagnosed with a condition for which there is no reasonable hope for curative treatment and from which they are likely to die. The term 'life-threatening' is applicable to children with conditions that may be curable but may also fail to respond to treatment<sup>4</sup>.

<sup>4</sup> For the purposes of the current report, the term 'life-limiting' will be used to encompass all children who qualify to access children's hospices.

### *1.3 The Evolution of Paediatric Palliative Care*

Over the last decade, consistency, reliability and cohesiveness in PPC has been aspired to (ACT, 2004; Mellor, 2011). In 2012, Together for Short Lives (TfSL) released their Charter iterating the expectation that all families with children who have been diagnosed with life-limiting conditions are entitled to individualised packages of care.

Where originally PPC adopted a hospital model offering medical care to children with a cancer diagnosis, it has developed into a community model largely driven by children's hospices. These are usually third-sector organisations aiming to provide individualised care, at home or in a hospice setting, to all children with complex life-limiting conditions. Their holistic and person-centred design has increased demand for the growth of hospices to provide a nationwide model of equitable care (Emond & Eaton, 2004). The way in which services are commissioned varies with some Local Health Authorities (LHA) valuing PPC resources more than others (TfSL, 2013a). Children's hospices without LHA funding are heavily dependent on charitable donations and volunteer staff support.

### *1.4 Challenges for Paediatric Palliative Care*

Despite the aspirations of TfSL and the movement towards a hospice-led model of care, there remain large gaps in service provision (TfSL, 2013a). A number of factors, such as perceived family need and commissioning agreements, influence whether families receive equitable and appropriate care (Grinyer, 2012). Without comprehensive multi-disciplinary assessment and ongoing review of need there is a danger that parents are insufficiently supported in their caring role, thus increasing their risk of experiencing mental health difficulties such as anxiety and depression (Lindstrom & Melnyk, 2012). Many families do not receive hospice care at the time they qualify for it (Grinyer, 2012) and this is likely to be a reflection of services' over-reliance on charitable funding which is unsatisfactory to fund services capable of preventing burn-out amongst parents and carers (Chambers et al., 2009).

The Department of Health policy document 'Better Care: Better Lives' (2008) recognised several challenges within PPC, including: unnecessarily high thresholds for accessing the full extent of PPC services required; poor coordination of services; reluctance to accept responsibility by budget holders for funding aspects of care and; lack of capability, capacity and resource to offer equitable care. Fragmented and inconsistent care was thought to result from a lack of cultural and social acceptance of death, having a smaller proportion of children with PPC needs when compared to adults, a shortage of specialist medical staff, and a lack of cohesion between organisational and managerial policy (Chambers et al., 2009; European Association of Palliative Care, 2009).

### *1.5 The Experience of Hospice*

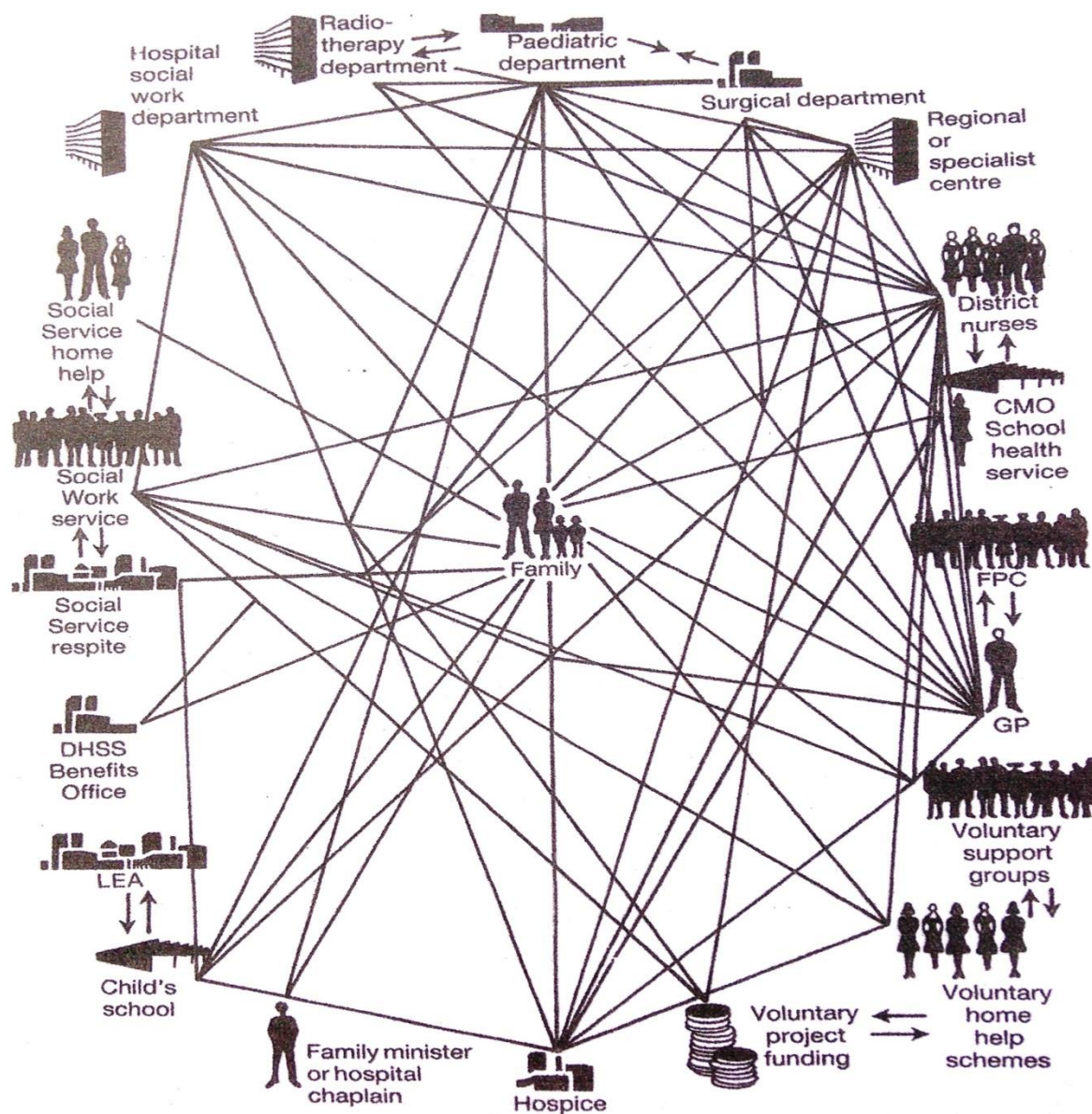
Helen House, Oxford, was the first children's hospice to open in the UK in 1982. It offered a pioneering model of care that led the way for the 43 subsequent children's hospices around the country (Chambers et al., 2009). These hospices provide a number of different services and have generally been established by individuals within local communities with the financial means to set them up (Grinyer, 2012). At present there is no formalised national strategy to develop children's hospices despite the recognised need for it (Brown & Warr, 2007).

Following the World Health Organisation's publication, 'Dying for Change' (2012), TfSL published a paper summarising the findings from a conference held to consider the experience of children's hospice care (2013b). The publication highlighted a number of criticisms of the current hospice model including that children's hospices were expensive resources caring for a minority of the dying and 'cherry-picking' those they care for. Children's hospices were perceived by some to be offering a service-driven model rather than a user-focused one which does not adequately meet user need. There were concerns about the continued limited evidence-base, felt to be insufficient to support the current model of

hospice, and about the growing population and increasing demand on hospice services (Fraser, 2012; TfSL, 2013b).

While there is a paucity of published research considering the experiences of families with life-limited children and their experiences of receiving hospice support (Price et al., 2005), there are some powerful narratives about the family experience. Gill writes about her experience from her position as a nurse and parent to a child with a life-limiting condition (2010). She describes resigning her post as a nurse and continuing to care for her son while navigating a “*maze of services*” equating to 32 different practitioners. She expressed feelings of frustration and intolerable uncertainty in her role; reactions strongly associated with grief (Carr, 2006).

Figure 2: An Example of Services Likely to be Involved with One Family (Baum & Woodward 1990)



For Gill, family resilience was determined by embedding a culture of fun, creativity and humour. Being supported by a community of other families facing similar difficulties, having immediate and regular access to specialist services, and involvement in services through joining parent committees was greatly helpful. This is one example to guide the effective future implementation of PPC services, yet further stories are required to thicken the existing evidence.

### *1.6 Psychological Models of Grief*

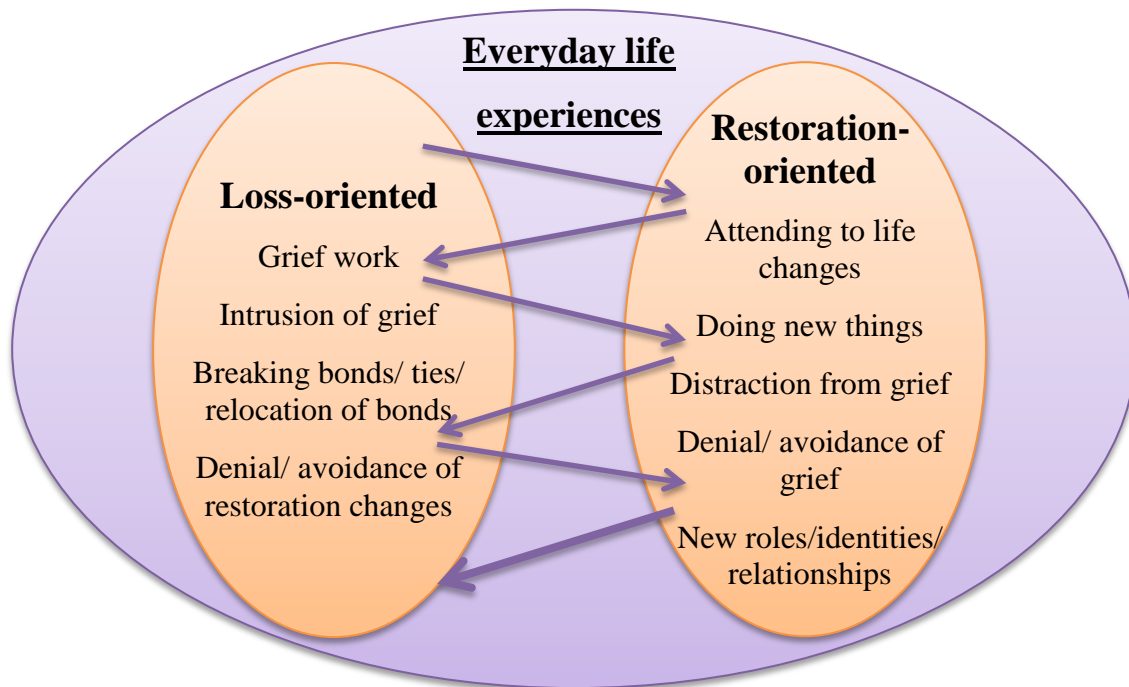
Grief, loss and bereavement are the core business of PPC. Parents who have lost their child to death are at risk of protracted, complex patterns of grief and bereavement (Carr, 2006). Even where terminal care may not imminently form part of a family's agenda, there are a number of losses, past and anticipated, characterising the family experience of caring for children with life-limiting conditions. An example may include grief associated with the realisation that the anticipated child development experience will not be realised (Hugger, 2009).

Grief processes are accounted for in most psychological theories. Early psychodynamic literature explains grief as a process prolonging the existence of the deceased (Freud, 1968). A family systems perspective suggests grief processes bring families together through their joint acknowledgement of loss and reorganisation of family roles, routines and responsibilities to account for the loss (Walsh & McGoldrick, 2004). Bowlby's stage model (1969) links grief to attachment through arguing that the function of grief is to seek 'proximity' to one's primary attachment figure. He purports that initial grief responses mark a protest against separation which is followed by shock, feelings of anger, and longing for what has been lost. Subsequent stages characterise a process of cognitive restructuring whereby detachment occurs and new attachments can be formed. Kubler-Ross (1969) offers another stage model of grief, characterising the process as a progression through stages of denial, anger, bargaining for extra time, depression and acceptance.

The Dual Process Model (Stroebe & Schut, 2001a) recognises individual differences within the grief process and proposes an unpredictable oscillation between the loss-oriented and restoration-oriented functions of grieving. This aspires to account for uniqueness and to help identify where individuals may be at risk of complex grief reactions (Stroebe & Schut, 2001b)



Figure 3: The Dual Process Model



More recent psychological perspectives move away from ‘letting go’ as a function of grief and encourage continuing relationships with the deceased. Klass et al. (1996) suggest that rather than saying ‘goodbye’, healthy grieving may be achieved through relocating that which has been lost so that a parent can continue to nurture the bond with their child; this demonstrates that death may end a life but not a relationship. This notion of continuing bonds (CBs) is present in the grief work that PPC services provide to families throughout the trajectory of their child’s illness.

Worden (2002) reframed the ‘stages’ of grief into four central ‘tasks’ to be accomplished, thus capturing both the objectives of the stage models and the notion of CBs: to accept the reality of the loss; to work through the pain of grief; to adjust to an environment without the deceased and; to find an enduring connection with them while embarking on a new life. He recognised the transient and individual nature of grief within his model and sets no time frame in which these tasks should be completed.

Rothaupt and Becker (2007), and Davies (2004), reviewed these published models of grief. They recognise the dominance of western perspectives within these yet also highlight their progression from pathologising, over-simplified models of the uniqueness of grief processes. Process-driven models are useful because they provide a seemingly simple conceptual framework to help us understand complex emotional phenomena. They warn that practitioners should be cautious of their potential to present a uniform and overly-simplistic approach to grieving.

### *1.7 Rationale*

In recent years, PPC in the UK has undergone significant development, reflected in the changing policy and climate as presented in the current introduction. Given this, the limited evidence into the perceptions and experiences of families does not adequately support an emerging hospice-led model of care. A robust evidence base is essential to enable hospices to improve their existing services in line with user need (Stokes et al., 1997).

Considering the perceptions of parents within these families would offer a rich insight into how families experience hospice services in the care of their child. Further understanding of the current hospice experience and what it means to parent a life-limited child might draw attention to a number of issues that could be used to inform service development and contribute to measuring outcomes for hospice use. The current research might also add to the evidence justifying future funding streams.

## 2. Aims and Objectives

The aim of the current research was to build on existing literature using qualitative data focusing on understanding the subjective experiences of families caring for children with life-limiting conditions accessing children's hospice services. The objective was to collect qualitative data representing the retrospective and current experiences of parents accessing hospice care in one region of the United Kingdom.

The following question was addressed: "What are the experiences of parents accessing hospice services in the care of their child?"

The focus was on the meaning that parents make of having a child with a life-limiting condition and what has and has not worked in their receipt of hospice services.

## 3. Method

### *3.1 Study Design*

A qualitative design was used to explore the experiences of parents caring for a child with a life-limiting condition accessing children's hospice services. A combined method of weekly diary entries kept over three months and semi-structured interviews aimed to enable free participation and invite participants to identify issues of importance to them. The combination of methods had several benefits. The diary method gathered data from the participants' natural, spontaneous context enabling the researcher to gain an insight into their experience with minimal influence of retrospective effects (Bolger et al. 2003; Iida, 2012). The interviews enabled participants to reflect on, validate and enrich the information provided in the diaries allowing the researcher to gain a fuller understanding of the experience and process of interpretation and meaning-making that the participant underwent.

### *3.2. Sample*

Convenience sampling methods were chosen to locate participants with experience relevant to the aim of the current research (Smith et al. 2009). Participants were recruited from two children's hospice sites across one region of the United Kingdom (UK). Homogeneity was achieved by participants being from the same geographical region, with access to similar hospice models. All participants were mothers who had cared, or were caring for, one child with a life-limiting condition. While this helped achieve a homogenous sample, the research was initially interested in the perspectives of both parents.

Inclusion criteria:

- Parents of children aged between birth and 18 years old with a life-limiting condition
- Where one or more family members were in direct receipt of support from one of three hospice sites within one hospice organisation

Exclusion criteria:

- Those unable to communicate with relative fluency in English, written or verbal
- Those without the level of literacy required to fully engage with the material presented by the research project
- Those without the capacity to offer their informed consent to participate

Smith et al. (2009) advocate for the use of between four and ten interviews for professional doctorate projects; nine parents were initially recruited to take part in the current research. One participant chose not to share her diary or take part in an interview. Due to child illness, two further participants were unable to take part in an interview. Therefore, the current research was informed by six corresponding diary and interview sets and a further two diaries; amounting to eight participants.

Table 1: Self-Reported Demographic Characteristics of Pre-Bereaved Participants

ID	Age	Ethnicity	Faith	Number of Children	Child Age	Child Gender	Contact with Hospice
Sam	39	White	Spiritual	3	11	Female	10 years
Emily	40	English	Spiritual	2	11	Female	8/9 years
Jenny	43	White/ British	Church of England	2	14	Male	11 years
Rebecca	35	White/ British	Christian	1	5	Male	3.5 years
Joanne	33	White/ British	Church of England	2	4	Male	1.5 years
Sarah	31	White/ British	Christian	3	3	Female	3 years

Table 2: Self-Reported Demographic Characteristics of Bereaved Participants

ID	Age	Ethnicity	Faith	Number of Children	Child Age Before Death	Child Gender	Contact with Hospice
Katie	36	White/ British	N/A	1	15 days	Male	6 months
Mandi	39	White/ British	Christian	2	17 hours	Male	18 months

### *3.2.1 Recruitment*

The researcher met with the hospice organisation and agreed strategies for recruitment, details of which are contained in Appendix E. Participants were provided with a number of forms which can be found in Appendices F to K.

Table 3: Participation Details

ID	Diary Method	Diary Reminder Method	Number of Completed Diary Entries During 12 Weeks	Interview Included?
Sam	Email	Email	13	No
Emily	Paper	Text	12	Yes
Jenny	Email	Email	8	Yes
Rebecca	Paper	Email	9	No
Joanne	Audio	Email	12	Yes
Sarah	Paper	Email	28	Yes
Katie	Email	Email	13	Yes
Mandi	Email	Email	12	Yes

### *3.2.2 Situating the Sample*

Participants shared a number of characteristics yet differed in the contact they had with hospice services in terms of duration, frequency and services accessed. Two participants were bereaved parents whose children had died as new-borns, six parents continued to care for their life-limited children. Participants accessed services by different means and at different stages in the trajectory of their child's illness.

### *3.3 Procedure*

#### *3.3.1 Feasibility, Ethics and Governance*

A feasible and clinically valuable area was identified and a project outline was formed in collaboration with three children's hospice organisations. Following an initial literature review to scope for similar research in the field of parent experiences of children's hospice, the need for further relevant published research was confirmed. A process of peer review by the participating children's hospice organisation, university staff and an independent service user reference group, recommended a number of amendments to the proposal. In February 2013 a National Research Ethics Committee (NREC) granted a favourable opinion for the research (Appendix M) and sponsorship was approved by the researcher's local Research and Development Office (Appendix N). A simultaneous application had been submitted to the Clinical Governance Committee of one hospice organisation who had collaborated in the planning of the project and that had committed to becoming a recruiting site. Permission was granted for an honorary contract so the researcher could commence recruitment in March 2013 (Appendix O).

A substantial amendment to include an interview element at the end of the diary process was accepted by the NREC and a favourable opinion was granted in July 2013 (Appendix P).

#### *3.3.2 Ethical Implications*

An informed contract of consent was established so that participants were made aware of the research process. This was achieved by providing them with a Participant Information Sheet (Appendix F) and Informed Consent Form (Appendix H). Questions were invited before, during and after their participation.

Confidentiality and risk was discussed with all participants at the informed consent meeting. It was explained that if the researcher was made aware of any risk issues, the policy of the hospice organisation and the researcher's recruiting NHS Trust would be followed to address these concerns. It was also explained that as part of the NREC approval process, the participant's general practitioner would be notified by letter of their participation in the research.

Transcripts were anonymised to prevent identification of the participant; they were password protected and stored on a secure university computer. Confidentiality was ensured through disguising identifying participant demographic information (Gabbard, 2000).

### *3.3.3 Transcription*

The seven written diaries were collated and typed-up by the researcher verbatim. Audio-recorded material from the six interviews and Joanne's diary were transcribed by a professional transcriber located and employed through the researcher's university. The transcriber was asked to follow Jeffersonian conventions on transcription (2004). This level of detail was deemed sufficient for an Interpretive Phenomenological Analysis (IPA) where the content of the text forms the focus of the analysis (Smith et al. 2009). In all interviews, background noise and interruptions were noted but removed from the script.

Once transcribed, material was checked for accuracy by the researcher which enabled familiarity with the transcripts before entering into the analysis. All identifiable names were removed and efforts were made to anonymise transcripts to protect participants' identities.

### *3.3.4 Interpretive Phenomenological Analysis*

Identifying themes from a phenomenological position was deemed appropriate to achieve the research aims; this facilitated an understanding of participant perceptions and how they attributed meaning to their experiences. Phenomenology allows multiple perspectives to be



valid, and can appreciate the experiences of all participants (Smith et al. 2009). An IPA was selected because it enabled the researcher to interpret the meanings that participants may have been unaware of. It also allowed for consideration of the wider context as perceived by the researcher, thus uniting both the participant and the researcher's perspectives (Eatough & Smith, 2008).

The diary transcripts were analysed using the six-step IPA guidance by Smith et al. (2009). The interview transcripts were not subject to a the full IPA but were used more flexibly to validate the diary narrative and facilitate a clearer understanding of participants' meanings. Example pages demonstrating the analysed diary and interview transcripts can be found in Appendices Q and R respectively. Each participant's data were analysed by first considering their diary and then their corresponding interview transcript before moving onto the next participant's data. This process was chosen to ensure that relevant themes emerging in their diary had been understood accurately and validated by the corresponding interview.

In adherence to Smith et al's. (2009) IPA guidance, the first step of reading and re-reading the diary facilitated the researcher's immersion in the data. The second step required an exploratory level consideration of content and language which was noted on the transcript, as demonstrated in the right-hand column of Appendix Q. The third step required the reader to identify emergent themes which were then transferred to the left-hand column of the transcript. Once these had been identified, they were recorded on notelets which were clustered together into areas of commonality and difference. Once this process had been completed, the corresponding interview transcript was read and re-read and a process of initial noting in the right hand column of the transcript (Appendix R), as per the first step of the IPA process, was conducted. Narrative that was thought to clarify, contradict or confirm themes corresponding to the diary, was highlighted on the transcript, transferred to notelets

and clustered with the abstracted diary themes; these clusters began to indicate preliminary emergent themes within each participant's data.

The fifth step of the analysis required completing the same process for the remaining diary and interview sets. Different coloured notelets were used for each diary and interview set so as to be able to maintain an ideographic focus and recognise where diaries were individually different. Step six required looking for patterns across cases to identify areas of recurrence; from this, emergent subordinate and superordinate themes became apparent. As this was a larger sample size for the purposes of an IPA study, themes were identified based on the frequency of their emergence within and between diaries as well as by the emphasis given to them by the participant (Smith et al. 2009).

The final step in this process was to locate quotes from the diary transcripts to illustrate emergent themes. All quotes incorporated within the current report were extracted from the diary narrative rather than from the interviews. This was for two reasons: to ensure consistency, as two of the diaries could not be paired with corresponding interviews and; to ensure accuracy as only diary data was subject to a full IPA while interviews were used as a form of participant validation.

### *3.4 The Forestructure*

The current research is concerned with participants' interpretations of their experience. A position recognising the individual interpretation within the participant's account, while also considering the wider impact of their context reflected within their data allowed the relationship between the researcher, the participant and the wider context to be recognised. A contextual constructivist epistemological stance was deemed appropriate to meet these aims (Madill et al. 2000) (Appendix S).

A number of methods to ensure methodological rigour were used. For an exploration of issues relating to quality and a declaration of the researcher's interest, see Appendices T and U respectively.

#### 4. Analysis

Due to the large sample for the purposes of a doctoral-level interpretative phenomenological analysis (IPA) research project, the emphasis of the analysis was placed on identifying key emergent themes for the wider sample<sup>5</sup>, illustrated by individual examples. The aim was to retain an ideographic focus while perceiving the messages of the wider sample (Smith et al, 2009).

Table 4: Research Themes

Superordinate Themes	Subordinate Themes
“Must get my Superwoman cape on”	Fighting the Face of Adversity
	Multiple Selves
	Accepting Unrelenting Responsibility
Attachment & Child Development	Being “over attached”
	The Longed-for Child
A “Rollercoaster” of Emotion	Grief and Uncertainty
	Powerlessness
	Hope and Faith through Serendipity
Transitioning Communities	Belonging and Shared Experience
	The Elephant in the Room: Death, Dying and Disability

<sup>5</sup> Themes were deemed ‘key’ if they repeatedly occurred within the individual participant’s data and emerged for six or more of the sample.

While themes for the current research have been set out in Table 4 as per the IPA guidance, there was much overlap between and within themes which has been addressed within the analysis and discussion sections.

#### *4.1 “Must get my Superwoman cape on”*

This superordinate theme consists of three subordinate themes reflecting participants’ perceived duty to “*work miracles*” (Joanne, 239) and “*soldier on regardless*” (Joanne, 319) when responding to numerous conflicting demands. The Superwoman metaphor presented in this theme characterises this duty and shows one way in which participants coped with the threats posed by their child’s life-limiting illness and the complexity of their grief.

##### *4.1.1 Fighting the Face of Adversity*

Within all diaries, participants depicted situations in which they responded to perceived threats by fighting against them. On some occasions fights were lost and a sense of hopelessness was described; at other times they felt triumphant and relieved to have been successful. By striving for the immediate and future needs of their child, participants took on a weight of responsibility which caused heightened levels of distress and frustration with healthcare systems and resource constraints. Other battles were characterised by the fight for their child to continue living, either in presence, or by resituating the memory of their lost child and seeking ways to continue bonds with them. All participants fought against the pain of grief.

*Sam: “when she was a baby and the consultant told us that they could do no more for her...We told her that if the life that lay ahead was too difficult for her to face, we would let her go with dignity and love her forever until we would be together again BUT we also told her that if she chose to stay and fight, we would fight every day with*

*her and we would match her strength for strength and she would never be alone. The next day she started to turn a corner and we still fight side by side.”(272)*

Sam’s optimistically presented fight for her daughter’s survival demonstrated her willingness to take on the unknown challenges presented by her daughter’s condition despite the compromises required of her family in so doing. Words such as ‘we’ and ‘us’, conveyed the family’s collectivist ethos; a unity that seemingly helped her approach difficult challenges with positivity.

Later in Sam’s diary, she described staying in hospital over several nights to fight against the adversity of her child’s life-threatening surgery without the supportive presence of her family.

*Sam: “I think I’m going to stage a mini protest and see if I can sleep in the playroom after hours because I can’t stomach the thought of leaving her [daughter] and being on my own.” (511)*

This is an example of where Sam’s Superwoman cape became less effective as a way of disguising her feelings of vulnerability. Having been separated from her key attachment relationships and familiar home environment where Superwoman had been a more powerful and adaptive defence, the bleak reality of her daughter’s critical illness became unavoidable; thus symbolising her kryptonite.

Joanne shared a poignant moment of despair emerging from her feeling of vulnerability having received news that her third appeal for expenses to pay for her son to travel to school had been unsuccessful.

*Joanne: “I unfortunately found myself sat in a corridor at Hospital sobbing...we sat in this corridor, me with him on my lap, crying my eyes out...I feel a bit fed up having to argue everything all the time...and having to constantly fight”(392)*

The six participants with life-limited children demonstrated their persistent battle against a multitude of different services that they perceived to be unwilling to share in the responsibility of their child's illness. There was a theme of fluctuating emotional energy between these women whereby they fought determinedly, intermittently regrouping to debrief, recharge and motivate themselves.

*Jenny: "This week has been overrun with 'Nappy wars'. The NHS has yet again changed supplier...For Harry this means either pads that cut off his leg circulation or are so big he walks like a cowboy who has lost his horse. Neither are suitable. The NHS has limited the type for cost effectiveness but doesn't seem to understand that one size doesn't fit all. It's these little battles that take up so much time and effort." (317)*

Jenny used humour throughout her diary to help her in facing her battles; despite this, she echoed the widely expressed frustration that services did not understand her child's unique needs and repeatedly made commissioning decisions without user contributions. 'Nappy wars' exemplifies one of a number of perceivably small commissioning decisions that had an enormous detrimental impact on families that felt they had no choice but to fight against them.

Bereaved participants also encountered battles against services. Although they did not actively share the frustrations of participants caring for life-limited children in relation to the support of services, they did echo feelings of disempowerment by services when they felt unheard and misunderstood. Communicating their emotions in a way that professionals and services might gain an empathic understanding was an enduring fight and a priority for them.

*Katie: “this is not some ‘step’ programme where you go through sequential stages... It is a whirlpool! ...I do experience moments, beautiful moments when I feel so connected to you Ollie but then there is another pull, another whirlpool.” (12)*

Katie’s reflections about stage models of grief, taught by the hospice to help her conceptualise the instability of her grief within a theoretical framework, in some ways served to minimise her attempts to work-through her internal conflict.

#### *4.1.2 Multiple Selves*

The six participants caring for children with life-limiting conditions demonstrated an intense identification with a number of roles required of them in order to sustain their child’s life. In aspiring to manage so many conflicting demands and cope with the emotional consequences of different roles, participants became engulfed within the role of caregiver and found it difficult to distinguish between this role and their identity. They demonstrated a perception of themselves with multiple identities, or ‘selves’. The caregiver ‘self’ embodied tasks that may be required of a nurse, paramedic, advocate and care-coordinator. This was also held alongside the demands of being a mother and a partner.

In managing the layers of responsibility associated with these identities, participants showed remarkable resourcefulness despite the significant stress they also reported. There was an emphasis placed on being prepared for all eventualities conveyed throughout these diaries.

*Jenny: “off we went to Euro Disney. We drive ourselves as he’s better in his own space. The organisation is unreal, medication, proof that the meds are his, doctors letters, feeds, pads etc. Three of us have one bag and Harry has 22!” (169)*

Packing was depicted as a major operation, managed successfully only as a result of extensive planning and organising to ensure preventive and reactive contingencies were in

place to respond to the acute threat of their child's decline in health. Joanne described an incident where her son had been violently sick and choked during a car journey.

*Joanne: "I had to literally pull up there exactly where I was—no pulling over or anything, quickly get myself into the back, get David into a position at which I could suction him...it made me realise again how difficult it can be"(432)*

While Joanne's mother and sister had been in the car, both familiar with David's care needs, they had been unable to offer the medical expertise required to help him. While particular medical knowledge and experience is required to offer this level of life-sustaining treatment, neither Joanne nor her husband had proactively taught the family how to administer this level of care. This reluctance to 'let-go' of some aspects of the caregiving role was reinforced when considering Joanne's use of hospice respite as she reported always staying with David during respite breaks rather than taking the opportunity to step away from caregiving and focus on her other needs. Of the multiple selves depicted amongst diaries, identification with the caregiving self was particularly strong. Given the extent of engulfment in the role, delegating some of these tasks to others risked a painful feeling of redundancy.

The level of vigilance required of the caregiving self was seen to prevent participants from satisfactorily meeting the needs of their healthy child. Five of the participants caring for life-limited children also parented healthy children and described a sense of guilt in relation to this identity as they felt unable to adequately fulfil a 'normal' parent role.

*Sarah: "We love our children all the same, Alex's routine takes a lot of time and she requires a lot of attention over her sisters, and we feel guilty about this...which is why hospice respite is so important."(331)*

In aspiring to meet some of the needs of their other children, participants found some ways to make use of the limited resources available to them, such as using respite when it was



offered. Despite this resourcefulness, these ways of coping were temporary solutions to alleviate feelings of guilt and shame and did not enable sustained respite from these feelings. The perceived requirement of knowing how to simultaneously meet the needs of two children with very different needs brought about a significant interrole conflict for participants.

#### *4.1.3 Accepting Unrelenting Responsibility*

All participants described resigning themselves to a persistent and unrelenting sense of responsibility. Responsibilities included: protecting their life-limited child from death or danger; continuing their child's memory after death; protecting their child's grave; meeting the needs of other family members and; concealing the taboo of death and disability from others. With the weight of such responsibility came heavy emotional burden which led to a longing for respite and further feelings of guilt for waiting for the hospice to offer them respite from their child's care, or from the intensity of their grief.

Joanne felt solely responsible for responding to the unpredictable emergency needs of her child when outside of hospital; she was always alert to the possibility that a crisis could emerge at any time.

*Joanne: "it's a huge weight on my shoulders, a huge responsibility...I'm pulled up on the side of the road...I'm in the middle of the road, I've got a child that's...continually still vomiting...who could potentially go into respiratory distress"(452)*

For the mothers of life-limited children, the uncertainty of their child's condition meant their diaries contained depictions of sudden and acute physical deterioration. This meant constant monitoring, sleeping beside their child at night and relying on their intuitive sense of their child's physical health status. Respite was the most sought-after way of preventing their own burnout.

*Sarah: "we usually don't get any respite in this time [school summer holidays] ...This is quite frustrating at times, it's tiring not having any support or break from our routine...It's a time when many of us with younger children and siblings could do with the respite in order to spend some quality/special time with our other children." (320)*

While participants with life-limited children sought respite through breaks at the hospice, bereaved participants sought emotional respite from the rollercoaster of their grief through talking therapy provided by the hospice. For all parents, the rationed respite availability was a concern as it seemed that even the most basic of activities were dominated by their child's needs or reminders of their child's death. Jenny encapsulated the extent of the intrusion into her own life; *"just having a wee on my own would be nice."* (75). A similar message is reiterated by Sarah who conveyed her resignation to the limitations of her life.

*Sarah: "Sadly many people, just like us don't have a social life, don't have adult time away from the home due to the simple fact that no one is confident enough to look after our complicated children!" (540)*

Respite provided a break from the intensive care needs of their children, or from the isolation of grief following the loss of a child in order to 'catch up' with normal day-to-day activities. While these opportunities were limited, finding time to pursue personal and social experiences was even more so. However, of particular interest when considering the pursuit of respite through the hospice was the passive way in which it was accessed by participants who waited for it to be offered rather than assertively pursuing it, as they might pursue other healthcare entitlements. This often meant that when it was received, it was of lesser benefit to them.

## *Summary*

Participants described an overwhelming sense of responsibility and reflected on the inadequacy of the support they received to meet their family's needs, access to which was a constant fight. In coping with these difficulties, they described layers of self-sacrifice and embodied multiple different roles to compensate and regain a sense of control. They struggled to access external resources for help and support, and were actively passive in accessing other resources.

### *4.2 Attachment and Child Development*

This superordinate theme depicts two subordinate themes demonstrating some of the most frequently arising challenges of parenting a child with a life-limiting condition. Attachment refers to the close symbiotic relationship between mother and child, formed to enable their child's survival. Strongly linked to the notion of attachment emerged the notion of the longed-for child able to pass through the expected stages of the child developmental trajectory. Participants grieved the loss of the idealised child, and found ways to manage this by seeking out experiences for their child and family that in some way met their need to achieve a normal family and improve the quality of their child's life. They also sought the birth of another child who would reach the expected developmental milestones and with whom they aspired to develop a less dependent style of attachment.

#### *4.2.1 Being "over-attached"*

Intense attachment relationships between mother and child ran throughout the diaries. Participants raising life-limited children acknowledged the dominance of this relationship, conceptualising it as an emerging phenomenon resulting from the repetitive threat of their child's imminent death. Bereaved parents related their own over-attachment through their preoccupation with their child's memory; Katie depicted this through poetry, "*always*

*together, never apart...you live on in Mummy's heart.*" (918). The complicated and challenging circumstances surrounding these children's lives and deaths resulted in an enmeshed relationship with their mothers. The trauma of raising a child with a life-limiting condition also impacted on the attachment relationship with subsequent children.

Jenny offered an insightful narrative identifying the misconceptions of others who seemed unable to empathise with the function of this attachment relationship.

*Jenny: "Harry's autism, low functioning and overattachment to me mean if he's at home it has to be Mummy. I've had social workers in the past say he's 'over attached', with a hint that I should have done something different. That winds me up a lot! For the first two years of his life we spent as much time in hospital as at home. Chris works, I had to give up work to care for Harry (which I don't mind at all). However I was always there, I became his constant when things were tough, the first person he saw after a massive seizure, the one who held him tight for yet more blood tests, the one he slept on all night when his breathing was bad due to Valium to stop him fitting. Yes he's over attached, but what the heck could I have done differently? Abandoned him in hospital and gone off shopping? I am his security, his constant. If he's with me, I look after him."* (93)

While Jenny appreciates this 'over-attachment' has a number of disadvantages, it acted as an incentive motivating her to meet the persistent demands of her son's needs with willing vigilance. The adaptive nature of this style of attachment becomes startlingly apparent when considering the alternative that Jenny implies; risking the end of her child's life. Given the difficulties participants reported in establishing resources to support their child to thrive, this innate maternal strategy enabled their child the best quality of life available to them.

For Mandi, whose baby son died a year before she took part in the current research, the relationship with her new baby daughter was an anxious experience in which she anticipated further grief.

*Mandi: "think I can cope with most things but the fear of losing her is massive. She is the Rainbow at the end of our storm but I am just waiting for the storm to come back." (546)*

The trauma of her baby's death resulted in an anxious attachment to her new baby where she frequently checked that Lilly was alive and breathing. This example demonstrates how the death of a child can have a significant impact on the attachment relationship with subsequent children.

Katie desperately sought an attachment to her deceased son and intently worked to find ways to continue their bond. She did this in a number of ways: seeking out serendipitous signs representing his presence; talking about him to people; singing to him in the hospice music group; writing to him in her diary entries and; creating art with him.

*Katie: "I went straight to the cemetery, straight to you. We sat together and finished our picture. So Mummy did get to create with you after all! :) I named the picture 'All roads lead to you' because they do little man. However crazy things get, you are my constant ray of 'son'shine. You will walk with me always. Thank you. Always yours, Mummy. Xxxxxxx" (66)*

In these endeavours, Katie lived out the key components for an attachment relationship that would encourage healthy child development. She was playful and creative throughout her diary writing, as a new mother might be in the first year of her child's life. However, a new mother might usually be socially reinforced by the curiosity of others in her child. Katie's son has no physical presence to demonstrate her position as a new mother to society.

*Katie: "I wanted to be praised about how I am with my baby, how I am so calm, comments like "oh your so good with him". But I was deprived of that." (1243)*

Rather than reinforcing her as a mother through praising her child, her child's absence gained awkward and avoidant responses, thus preventing her from experiencing this compulsory element of the attachment relationship. She described this as "*living in purgatory of my experience of motherhood*" (695) and "*EAS 'Empty Arm Syndrome'*" (694), a concept shared by the other research participants who perceived awkwardness from others in relation to their disabled or deceased children. These avoidant responses from wider society served to strengthen the attachment relationship between mother and child as if to compensate for the absence of other social networks from their families' lives.

While this intense attachment served a number of adaptive functions, it was largely depicted as exclusive to the relationship between mother and child with fathers presented as more emotionally inhibited and usually in the role of the family breadwinner. This family model may be an effective way for a family to sustain itself when raising a child with such complex needs, or who are living through child loss. However, such exclusivity within the relationship between mother and child posed a danger of preventing access to others. Fathers, the family and the wider community were at risk of entering into a cycle of reciprocal rejection which was presented as being an isolating experience for all involved.

#### *4.2.2 The Longed-for Child*

The longed-for child represents the angst participants felt in recognising their child would not progress through the normal child developmental trajectory. Before the birth of their child, participants had expectations of how their child would develop and grow, many of which would have been based on socially constructed expectations of the stages of child

development. Their feeling of disappointment that this expectation would not be actualised resonated throughout the diaries.

*Joanne: “for a parent to have a child at a party that doesn’t understand and doesn’t want to participate in the activities...hasn’t got the ability to just go and sit with the other children and integrate and play, that’s really difficult.”(360)*

Events such as children’s parties highlighted the developmental gulf between Joanne’s son and other children of the same age. Participants experienced this as a personal loss and grieved on behalf of their children for the life they would not lead. This strong sympathetic identification with the experiences their child would not have, further emphasised the strength of the attachment between mother and child.

Comparisons were drawn between their family’s position and that of other families, for example, Rebecca described feelings of frustration emerging from a visit to family friends who had a young daughter. She found it difficult to hear their concerns about their normally developing child when compared to her own child and judged their challenges as trivial in the context of Toby’s life-threatened position.

*Rebecca: “We want to yell at them sometimes to stop worrying and start enjoying as the stuff they worry about, really isn’t an issue. We wish Toby would get cross as he wants an ice cream, or would run off to see the ducks, we wish we could decide at teatime to go for a walk to the park, or pop in to see nanny and grandad for tea, but we can’t”(91)*

By listing the things her friends’ child was able to achieve, and comparing them with her own child’s limitations, she projected her frustration and longing for Toby to be as able and healthy as their child. This frustration demonstrated how unacknowledged barriers between these mothers and those without the challenges presented by life-limited children arose. For

the other family, expressing seemingly normal parental anxieties to Rebecca served only to draw her attention to her child's disability and her unachievable wish for Toby to have normal childhood experiences. There was an expressed message that families who did not share the experience of having a life-limited child, could rarely 'get it right' as they served to be a source of painful comparison and evoked feelings of resentment within participants.

Katie's grief following the death of her son allowed her to continue a connection with him, yet physically she had not been able to live-out the experience of parenting that her body was prepared for following birth. She sought another pregnancy to assuage her body's readiness to be a mother.

*Katie: "the need to raise my child, to be a busy mummy, the sleepless nights, the teething, desperately wanting to have a sibling for you baby boy. Every month that comes, every period, is loss all over again. Mummy so desperately wants her arms to be full again. It is torturous little man. There is only one answer to that problem and that is to be pregnant again. When that doesn't happen, it is so hard to take." (236)*

When Katie's longing for another child was not fulfilled, her grief was reignited and she became stuck in a cycle of hope and disappointment.

Having another child was a way in which six participants felt able to meet their need to parent a normal child. During their participation in the current research, Katie shared her determination to become pregnant, Mandi gave birth to another baby and Joanne became pregnant with her third child. Only one of the other parents did not have another child. Becoming a parent to a 'normal' child triggered comparisons with their life-limited child, in life and in death.



*Mandi: "I had a rather emotional experience as I sat holding Lilly [new baby] ...I felt very sad, missing him [deceased baby] and wishing he was here. Also the poignancy of the warmth of her and the coldness of him." (390)*

Mandi was reminded of her son's cold state in death. While Lilly brought joy, she was also a reminder of what had been lost; this helped her both connect to her dead son while also igniting her grief.

Achieving life beyond illness and enabling their child to engage in 'normal', developmentally-appropriate activity was recognised as an important way for their child to experience a richer quality of life. This was especially difficult to achieve given that the context of death, dying and illness that was central to all participants' diaries and often sabotaged their successful pursuit of normality. Due to the challenges restricting their access to normal experience for their child, success provided cause for great celebration and enabled participants to gain some of the feelings of satisfaction they longed for from their parenting experience. Rebecca and Sarah illustrated their joy at witnessing their children having normal experiences.

*Rebecca: "One little girl came over and asked if she could dance with Toby! [at a party] She held his hands and jumped about. I nearly cried... What a sweet, beautiful moment." (77)*

*Sarah: "I carried Alex down to the seafront as we wanted her to experience what the others could-dipping toes in the water" (249)*

Through these experiences, participants progressed towards fulfilling their longing to make their children's lives worth living, although the perpetuating sense of grief could not be forgotten.

## *Summary*

Strong yet enmeshed attachment relationships fuelled participants' commitment to fend for their child and to strive for the best possible quality of life. Participants' conveyed a frustration with perceived judgements from wider society that pathologised the attachment relationship despite their lived experience evidencing that it was, in many ways, an adaptive motivating force, enhancing their child's quality of life. For bereaved parents, intense attachment to their child through grief enabled them to continue bonds with their deceased child; a mixed blessing. Alongside this powerful attachment phenomenon, the reality of the longed-for child was emphasised through comparisons made with families of children without life-threatening diagnoses, and through seeking the birth of other children who would reach expected developmental milestones. Comparisons with other families' children, or giving birth to another child able to achieve expected developmental milestones, could not satiate their need for normality for their life-limited child. Only successfully managing to provide normal experiences brought some relief from the longing for their child to be normal.

### *4.3 A "Rollercoaster" of Emotion*

All participants recounted a number of traumatic encounters with death and illness which highlighted their underlying existential anxiety. This theme explores three subordinate themes impacting on the emotional resilience of participants. The intensity of current and anticipated grief, along with their sense of powerlessness and uncertainty, was mediated by hope and faith inspired by serendipitous events serving to motivate them to "*soldier on regardless*" (Joanne, 319).

#### *4.3.1 Grief and Uncertainty*

Participants grieved a number of child-related losses and grieved in anticipation of further loss. In managing the uncertainty of death, participants found ways to emotionally remove

themselves from the existential anxiety they held for their children. Separation from this worry was achievable given the nature of day-to-day demands. However, sometimes the bleak reality of the fragility of living children, and the absence of children who had died became more vivid.

*Rebecca: "They put us in the ambulance and then drilled a needle straight into his shin bone...He cried and cried, but was so brave it broke my heart. All the time I was thinking this could be the day we say goodbye to Toby, but hoping and praying he would pull through...Riding in the ambulance with him so poorly, is like a flash forward to the future at some point, but the outcome will be very different...One day we won't be so lucky to bring him home again. This thought never leaves me, but I learn to deal with it." (159)*

Experiences like this were frequent for participant's caring for children, particularly in the winter months where chest infections could be fatal. In a similar way, bereaved participants experienced fluctuating grief. This was within and between diary entries, evidencing the unpredictability and transient nature of participants' grief. Mandi's traumatic experience of grief from the death of her baby resulted in her unrelenting fear of further loss in the birth of another baby during the current research.

*Mandi: "I was very frightened...I'm just waiting for something else to go wrong... I know I sound very dramatic but I think with me it's the fear of the fear. I cope pretty well with the crisis itself but the unknown I'm not good with." (448)*

Mandi's fear of uncertainty stemmed from the death of her previous baby as she feared a repetition of events that might have separated her from her subsequent child.

Uncertainty in the context of child life-limiting illness was a persistent threat that all participants reported left them feeling vulnerable and afraid. Participants were frequently

exposed to the reality of the death and illness of their children and often had no alternative but to manage the emotional consequences of this uncertain certainty through acceptance. Immersing themselves in the hospice community was one way of achieving this (Section 4.3) along with engulfing themselves in the demands of multiple identities and defending against distressing feelings by the disguise of the Superwoman cape which enabled them to form some positive reappraisals of the challenges they faced (Section 4.1).

#### 4.3.2 Powerlessness

The unpredictable nature of grief contributed to participants' sense of powerlessness in controlling their circumstances and managing their emotions. This theme portrays another form of powerlessness associated with services involved in the care of their children. Joanne's reflections in her recollection of a commissioning meeting demonstrate how this manifested in participants' diaries.

*Joanne: "We had the commissioner who was very confrontational, she was very unprofessional...we've been without a care package for 22 weeks now and we get no sleep overnight and struggle day-to-day...I'm really, really quite saddened by this woman's approach towards us and how she feels...she didn't seem to have any empathy whatsoever for our situation...it just brings me back to that huge frustration for a parent caring and looking after a sick child...we're told that there isn't any help available...this is the lady with the purse strings so very, very, very, yeah, very frustrating meeting. And just feel a bit vulnerable afterwards, you just feel a bit, you just feel sad." (64)*

An overwhelming sense of despondency and frustration emerged from Joanne's commissioning experience. A recurrent absence of understanding, empathy, clear communication and commitment from services was evident across diaries. Some participants reached states of desperation.

*Joanne: “please, we keep asking for help but no one seems to be listening and it’s really, really sad...we are really struggling, we are really struggling”(299).*

Participants felt there to be a distinct absence of service user (SU) involvement in commissioning decisions. Even where organisations advertised their collaboration with SUs, the extent of this was negligible and was sometimes perceived to be tokenistic.

During the course of the current research, two participant families required care from one hospice in their transition between hospital and home. Emily’s family was the first family to experience this level of care from the hospice. There were a number of challenges her family encountered during their stay which were fed back. She hoped that, while her family’s experience had been difficult, her recommendations about potential changes that could be made in the future would be valued.

*Emily: “I hope that the information serves as a good example of the way a family can work together with the hospice to look at change and improvements”(299)*

Some months later, Sam’s family requested a similar care package which was initially accepted but later cancelled. Sam and Emily both expressed the view that the cancellation had occurred following the hospice’s review of the pilot that had taken place with Emily’s family. This left Sam and Emily feeling the hospice’s initial positive response to her feedback had been disingenuous. Sam remarked, *“once again I feel they have not listened to our actual situation”(4).*

The theme of powerlessness was also apparent for bereaved participants. Mandi and Katie’s sons were buried in the same cemetery and both struggled with the cemetery’s rigid rules.

*Mandi: “When we got to the cemetery I noticed that a little dolphin on a stick, which had been included with the flowers I’d previously put on, was missing...when you take*

*considerable care and are not placing items which are large or dangerous or offensive in any way and they are removed it can be extremely distressing.”(128)*

The lack of consultation in the decision to remove items from these graves was strikingly insensitive and echoed earlier messages reflecting a lack of compassion and understanding for the emotional pain and difficulty encountered by this population.

#### *4.3.3 Hope and Faith through Serendipity*

Serendipitous and spiritual beliefs were reflected by six participants; all participants conveyed a sense of fluctuating hope. These elements were particularly present in the diaries of the bereaved parents and represented their desire to continue bonds with their children. By developing their belief in serendipity and spirituality, participants gained a stronger sense of hope which alleviated the painful feelings of grief. Katie’s references to serendipity, faith and hope were strongest; the fluctuation in her connection with these elements mimicked the pattern of her grief and ran throughout the diary.

*Katie: “My Hope died the day they told me that you wouldn't survive-the worst day of my life. For what is life without hope?”(241)*

*Katie: “Mummy walked around every alcove, peering in every creJoe! Until she found a statue of Mary & Jesus. A mother holding her child on only what can be described as ‘clouds of heaven’. They glowed together...I felt instantly connected to Mary and her suffering. All that she went through to her beautiful son and to lose him. I almost felt frozen in time with their pain.”(501)*

Several of Katie’s diary entries were written while she and her partner visited France. Her trip bore a powerful likeness to the traditional notion of a pilgrimage on which she went to seek a spiritual connection with her son. Through serendipity she recognised she could transport her

son with her in spirit; a vehicle towards relief from the separation anxiety she experienced from leaving her son's grave behind.

Despite her anxiety about giving birth to another child, Mandi was also able to recognise signs that her son may be with her.

*Mandi: "As we are driving to the hospital on Monday morning there is a rainbow, it's strange, there is a sense of calm and everything seems to be falling into place." (317)*

Katie and Mandi's faith in serendipity was usually conveyed through some natural or biblical form. Frequently reoccurring symbols included: butterflies; weather; animals; and; Mary and Jesus. These symbols are associated with sensory experience. If their children were living, they might be integrated into a mother's repertoire to stimulate their child's development through play. These elements link to the theme of attachment between mother and child (Section 4.2) and act as a way of continuing bonds between them despite the physical barriers between life and death. The stronger the sense of attachment to their child, the more faith they had that their child was with them; this brought relief from their "rollercoaster" of grief emotions.

### *Summary*

Participants reported experiencing frequent reminders of the reality of their child's death; a haunting awareness that they could rarely escape. While death was a certainty, the uncertainty of the variables surrounding this reality caused them great distress. Uncertainty also underpinned the experience of having another child which was a conflicted emotional experience of longing and fear. They also described the powerlessness they felt in navigating the services involved in their child's care. A distinct absence of SU involvement was highlighted through the lack of understanding expressed by many of the services. In managing factors that posed risks to their resilience, hope was maintained through faith in

serendipity. In combination, these emotions felt unpredictable and constantly changing, as a rollercoaster ride may be.

#### *4.4 Transitioning Communities*

Membership to a community of like-minds, and having the opportunity to contribute to establishing this community, was another way of coping with the stresses in participants' lives. Community membership provided purpose and meaning while also meeting their need for support and empathy from others able and willing to understand their experience. This theme consists of two subordinate themes relating to relinquishing membership of one community and forming a new one.

##### *4.4.1 Belonging and Shared Experience*

A strong community was formed between mothers accessing the same children's hospices. The sense of community was stronger for those accessing one of the hospices that ran a number of projects during the course of the current research. Increasing opportunities for community involvement strengthened participants' sense of community membership.

Through forums facilitated by the hospice, participants could access help and support in relation to the care of their children. During her participation in the current research, Sarah's child was injured during an unwitnessed seizure. Subsequently, Sarah's family were subject to a safeguarding investigation which caused her to query her ability as a mother.

*Sarah: "The past 24 hours have been totally overwhelming and I needed to speak with others who may have been through a similar experience, so I turned to the parents support group that has been set up on Facebook. It was very comforting to hear that many hospice families had gone through similar and it seems that children with very complex health conditions are prone to unexplained injuries. Having felt like the world's*



*worst mother for not knowing the cause of Alex's injury, I now felt completely normal" (115)*

Accessing a forum of other mothers using similar services normalised Sarah's experience and illustrated how powerful shared experience within communities can be.

Reciprocating gained participants a feeling of personal reward. Contributing through raising awareness of the hospice, fundraising and participating in activities achieved this. Sarah describes the satisfaction she gained from taking part in the music group performances.

*Sarah: "The performance was recorded... to raise awareness of the profile of the children's hospice. To spread the word about the amazing work that goes on here, and it was a pleasure to be part of that." (448)*

A number of motivations drove participants to raise awareness of the hospice, for example, it helped establish funding to resource the hospice while also serving to educate wider society about their ostracised community.

Several participants drew attention to the controversy associated with integrating pre-bereaved and bereaved families in hospice groups. Sam describes her disagreement with the segregation of families who had lost their children and those who continued to care for their children.

*Sam: "To think that our music group has staff, parents and bereaved parents I feel that it shows the bereaved and non-bereaved can be happy together and spend time together." (265)*

Concerns about split groups arose repeatedly within and between diaries. While these families felt segregated from wider society, they also risked segregation within their hospice

community. Mandi's experience demonstrated why the hospice might have been ambivalent about integration.

*Mandi: "Sometimes I feel I'm not sure I should be there [the music group] and feel almost like I am intruding as I don't share the experience of caring for a sick child as Jaq was only 17 hours old when he died. I worry that I could be seen as the dark side to come and that some people don't want to see or be reminded of that. However, although that is very negative I definitely feel that the positives far outweigh the negatives and that those feelings are more within me and not other people"(62)*

The most resounding message reinforced that community participation and togetherness was mostly advantageous. This was because, while participants' experiences were understood to be unique, there was recognition that their circumstances were similar.

*Sam: "the same shit seems to be an issue, regardless of age, needs or any other change!"(391)*

There was an underlying frustration that participants were fragilised<sup>6</sup> by the hospice. This perceived fragility evoked an overprotective response from hospice staff which was disempowering to participants and dismissive of the resources they had previously demonstrated were available to them. Achieving the balance between encouraging resilience and protecting families from unnecessary trauma was difficult for the hospice to achieve. In their disorganised allocation of respite care, hospices conveyed the message that parents must be resilient enough to cope without structured respite support. In contradiction to this, they were overly cautious of the potential emotional impact of integrating bereaved and pre-bereaved parents' support groups.

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<sup>6</sup> To perceive fragility and undervalue the effectiveness of resilience and coping resources

Within the current research, participants demonstrated resilience and embraced external curiosity in their community.

*Emily: “[the researcher] has just called to discuss progress. I love how she threw herself into working with us on the [music group]-it was very brave of her!”(194)*

Participation in the current research was seen by several participants to be a positive way of taking an active role in improving services and making a contribution to the hospice community. In contrast to this, staff within the hospice conveyed ambivalence about facilitating recruitment to the current research in the event that it may increase the emotional burden for hospice users. This was especially apparent when considering the recruitment of bereaved participants who were perceived to be the most fragile.

#### *4.4.2 The Elephant in the Room: Death, Dying and Disability*

Death, dying and disability underpinned all diaries. Participants reflected the perception of these things by wider society as taboo; topics that raised internal discomfort in others. ‘The elephant’ was dealt with by employing a number of defences such as denial, distortion and projection.

*Sarah: “What’s really annoying is the disapproving looks and mutterings other people make about us being parked in a disabled space...like we shouldn’t be parked there, it’s not a mother and baby space, she doesn’t look very disabled etc!...We get this everywhere we go”(226)*

This corresponded to a perceived misunderstanding and feeling of rejection by wider society. This misunderstanding was also within participants’ family and friendships, yet expressed more passively.

*Rebecca: "They will ask how Toby is, but not talk to Toby themselves or say hello to him. I'm not sure why? It's like he's not a person, or maybe they are unsure how to talk to him as he doesn't talk back?...I get cross, because people will...forget about talking to Toby. Yet I do know they care very much for him." (134)*

Rebecca tried to make sense of the awkwardness that others experienced in response to Toby's disability. She recognised that communicating with Toby would be difficult because he could not respond but she continued to be frustrated that this 'disabled' him from communicating with others. Mandi described a similar experience relating to her bereavement.

*Mandi: "One of my mother in laws first comments when she found out I was pregnant was "lets hope this one works out better than the last". That really upset me, it made me feel that Jaq didn't matter and didn't really exist." (221)*

These experiences demonstrated that others struggled knowing how to communicate about death, dying and disability so it remained the elephant in the room; the unnamed phenomenon evoking existential anxiety.

Katie introduced a further complication to this dilemma by recognising that she hid emotion by projecting a false-self to prevent other people experiencing difficult emotions. Her only outlet to express her true self was through therapy.

*Katie: "The feelings you have are horrendous and I am not sure how my friends or family could handle hearing that, so having someone to talk to is so important. Not fearing that you will upset the person hearing it." (229)*

Katie's interview reinforced that she took responsibility for the feelings of others by her frequent apologies to the researcher for talking about grief. This was also noticed within other participants' diaries. Masking unhappy feelings was less transferred to the hospice

community setting where difficult emotions could be shared, explored and empathised with. While the wider community might not have been able to tolerate such difficult liaisons with death, participants also struggled to facilitate the community's understanding. A dynamic of guilt and frustration between the two camps was perceived. This may go some way towards explaining intermittent national fundraising events such as Comic Relief which hooks into these feelings of guilt and awkwardness while helping the wider community to manage it through sponsorship compensation.

### *Summary*

Participants found belonging to a community of other parents, developed through opportunities presented by the hospice, to be an invaluable resource. The sense of community provided access to a reciprocal support network of others who experienced similar circumstances. This normalised difficult experiences, offered access to an expert resource and provided a chance to contribute; especially necessary because of participants' perceived exclusion from their wider community who were unable to understand or respond to their needs.

## 5. Discussion

In addressing the paucity of literature considering families' experiences of paediatric palliative care (PPC), the current research aimed to address the question: "What are the experiences of parents accessing hospice services in the care of their child?" From an interpretive phenomenological analysis (IPA) of eight reflective diaries and six corresponding interviews emerged four superordinate themes: "Must get my Superwoman cape on"; Attachment and Child Development; A "Rollercoaster" of Emotion and; Transitioning Communities. Some pertinent elements within these themes in relation to relevant literature, together with the clinical and research implications of these findings are discussed.

### 5.1 *“Must get my Superwoman cape on”*

This theme demonstrated participants’ attempts to satisfy the demands of a number of conflicting roles including caregiver, mother and partner. The heroic analogy of Superwoman conveys participants’ fight for the best quality of life available to their child and family, or to continue a bond with their deceased child.

The notion of the ‘Superwoman strategy’ as introduced by Polasky & Holahan (1998) refers to mothers who dedicated more commitment, time and energy to meeting the demands of multiple roles as opposed to renegotiating or delegating tasks within roles. In this study, mothers using the Superwoman strategy perceived all tasks to be within their capability and thus were at increased risk of experiencing mental health difficulties. In the context of the current research, a central part of being Superwoman involved fighting to access limited healthcare resources in the care of their child. This illustrated participants’ difficulties in the delegation or renegotiation of tasks to others due to factors outside of their control. Therefore, the Superwoman strategy was especially pertinent as a concept to describe how participants managed the demands of their child’s care by relentlessly dedicating their time, energy and commitment to the role.

Parents of children with chronic illness commonly report that they have few reliable and sympathetic support networks to delegate to (Atkin & Ahmad, 2000), by engulfing themselves in the tasks of the multiple roles required of them, participants felt less vulnerable to the increased risks of burnout presented by reliance upon the Superwoman strategy. Engulfment within their roles intensified as outside activities diminished and child dependency increased. Role engulfment can be conceptualised as a loss, or reorganisation, of the original self-concept (Skaff & Pearlin, 1992); thus participants’ self-concepts became tantamount to the requirements of being an effective caregiver, mother and partner. Following the birth of their life-limited child, aspirations and fantasies about the life they

aspired to lead, including the idealised child they had hoped to have, were re-evaluated in line with the reality of their new circumstances (Hugger, 2009). Striving for superhuman achievement within these new roles enabled them to avoid the reality that their initial hopes, dreams and aspirations would not be realised and their subsequent feelings of disillusionment in the loss of the idealised child corresponding to this.

Participants' struggled to escape the reality that their newly formed selves were persistently threatened by redundancy which would be brought about by their child's death. Complicated grief for the loss of their child and for the loss of their identity was an anticipated certainty. Casting themselves in the virtuous and omnipotent role of Superwoman served the function of enabling themselves and those around them to be distracted by this identity while it also motivated them to strive to 'fix' their child, as reflected within their many battles with healthcare services. Participants experienced ambivalent feelings of love and anger evoked by the intense dependency of their child who kept them captive within their caregiving role (Pearlin et al., 1990; Brinchmann, 1999). The 'Superwoman cape' acted as a defence against vulnerability and helplessness that arose from the emotions evoked from losses of the past, present and future; their intolerable feelings of failure as a parent and their own death anxiety (Ellman & Reppen, 1997; Yalom, 2008). These feelings of vulnerability and helplessness were also relevant to bereaved mothers who were held captive within their identity as the grieving mother. Without the physical presence of their child, fantasies of their child as ideal were able to continue as their child's memory lived on, yet the consequence of this was to prolong their distress. For these mothers, their Superwoman cape hid their intense grief and perception of having failed to sustain their child's life.

Considering Superwoman as an omnipotent defence goes some way towards explaining participants' ambivalence to pursue respite services and train family members to take care of their life-limited child. Support and respite risked heightening their awareness of

the reality beneath the cape. Without the full demands of their child's care, both the temporary loss of their caregiver self, paired with the recognised loss of their previous self before the birth of their child, risked time to reflect upon distressing feelings of grief and failure (Brett, 2004). This defence was reinforced within the hospice culture which was faced with a dialectical dilemma: participants were perceived to be both heroic and fragile, and achieving a synthesis between these two poles was a constant battle. For example, Joanne described feeling "*humbled*" by her observation of a family accessing hospice support in the end-of-life care of their child. Through comparing herself with this family, she identified herself as weaker in contrast to her perception of this family's resilience. To Joanne, there suddenly became an accentuated difference between her family, with a child who will one day prematurely die, and the other family, with a child that was imminently dying. Her 'humbling' left Joanne with the sense that she should be stronger and her feelings of helplessness were more vehemently defended through a closer identification with Superwoman. The strength she perceived of the other family acted as a vehicle motivating this.

By allocating families an unscheduled annual respite entitlement, the hospice communicated its rationed service availability which in turn indirectly reinforced participants' reliance on Superwoman as a defence rather than seeking respite. Had respite resources been offered consistently, participants' may have come to depend upon their entitlement which the hospice may have later had to withdraw given the depletion of funding streams.

Social perceptions of third-sector organisations are influenced by publicity geared to raise funds to maintain these organisations which often use sympathy-evoking methods to achieve these ends. In contrast, the National Health Service (NHS) constitution advocates that the NHS "belongs to the people" and makes a number of assertions relating to the rights of



the general public in accessing healthcare, iterating the message that ‘the people’ have choices about the care they receive (Department of Health, 2013). The different cultural impacts these messages have are significant; the former evoking a feeling of entitlement and the latter of gratitude. This was reflected in participants’ fight for their children to receive the full breadth of NHS services and offers further explanation for their passive approach to receiving hospice support.

Participants also considered respite to offer a predominantly emotional function that would meet their own emotional needs; the message this conveyed was that the physical health needs of their child should be prioritised above participants’ own mental health needs. This was reflective of the wider national context relating to parity between physical and mental health discussed in the recent occasional paper by the Royal College of Psychiatry (2013). There is an acknowledged need for a whole-person integrated approach to mental and physical healthcare yet, given that some mental health budgets are currently being cut to meet the needs of physical health services, succeeding in achieving this parity has been, and may continue to be, challenging (Fritz & Kennedy, 2012). Participants demonstrated responsibility to be active facilitators in their family’s mental health and more passive when meeting physical health needs. This ‘done to’ rather than ‘done with’ approach to physical healthcare may be a reflection of the setup of the NHS which manages physical health by encouraging the patient to take a passive position in their physical health treatment.

### *5.2 Attachment and Child Development*

Attachment can be defined as the disposition of the child to seek proximity to, and contact with a primary caregiver and is most necessary in certain situations, such as when a child is frightened, tired or unwell. The primary caregiver’s provision of a nurturing environment of trust and security that holds, contains and provides sufficient space to their child aims to enable the child to individuate and grow to become autonomous (Ødegård , 2005). The

attachment system of the infant forms one half of the social bond uniting parent and child and this is completed by a reciprocal caregiving system provided by the parent (Solomon & George, 1996).

In the context of child life-limiting illness, as identified by participants in the current research, some of the functions of this reciprocal attachment relationship could not be fully realised as the complexity of their children's conditions prevented them from achieving individuation or autonomy from their mother. Therefore, the tasks of the relationship were redefined to accommodate the chronic nature of child illness, the degenerative nature of their condition and the persistent threat of death. While the disillusionment of having a child unable to attain anticipated child developmental milestones risked demotivation within their caregiving role, the profound severity of their child's disabilities enabled them to reorganise their caregiving representational system. This in turn facilitated their better recognition, understanding and acceptance of their child's needs while adjusting their expectations of their child's development to become more realistic (Howe, 2006).

A number of crisis situations were presented within participants' diaries whereby their children survived only because of their intuitive and immediate responses to their child's physical decline. For these children particularly, attachment was directly associated with survival; in life and in memory. The traumatic nature of giving birth, multiple complex medical interventions and relentless treatment regimens jeopardised the crucial early stages of the attachment relationship (Bowlby, 1980; 1982). Developing a more enmeshed and dependent style within the attachment-caregiving dyad maintained the participant's proximity to their child, thus creating a more secure base from which their child could effectively be cared for (Ainsworth et al., 1978). Sam identified this phenomenon as 'over-attachment' and, in line with the perspectives of the other participants, deemed it necessary to enable her child to thrive in life and in memory. Ainsworth's (1978) work on attachment captures the intensity

of the bond between mother and child within the enmeshed attachment style and also reflects the resultant anxiety and anger that can be present within these relationships. The children of participants in the current research were unable to communicate their experience of their relationship with their parents due to a number of functional and sensory impairments, yet an ambivalent attachment style was identified by their mothers. These feelings were defended against by the Superwoman cape as discussed in Section 5.1.

One participant, Emily, was not the biological parent to her child. The differences between her experience of the attachment relationship and that of the other mothers illustrated the innate, biological functions of attachment. Emily's diary demonstrated a less enmeshed attachment relationship in which she protected more personal time for herself and shared the responsibilities of her child's care with others, also reporting fewer feelings of guilt in requiring respite care. Through this example, Emily highlighted that the attachment relationship and role engulfment were interlinked (Section 5.1). Having a stronger engulfment within their caregiving roles enabled participants to experience the demands of the attachment relationship more positively, and ambivalence about the relationship less intensely (Brinchmann, 1999). Despite these ways of coping with their child's dependency, the attachment relationship could not offer the reward that participants longed to encounter through witnessing their child's individuation and autonomy. In place of this, participants placed great weight on the reward experienced by their child's successful engagement in normal, developmentally-appropriate activities.

Participants demonstrated a preoccupation with the judgements of others who imparted upon them views influenced by westernised constructions of attachment and dominant discourses around mothering (Horwitz, 2003). The notion of 'over-attachment', was pathologised by professionals involved in the care of these children. More recent cross-cultural perspectives on attachment challenge this negative perception of enmeshment and

suggest that in some cultures, intense attachments such as these can be more adaptive in the context of different cultural practices (Quinn & Maggeo, 2011). As discussed in the current research under the theme of ‘Transitioning Communities’ (Section 5.4), the PPC community thrived by establishing its own cultural norms and values which may challenge traditional westernised expectations of maladaptive attachment styles.

In addition to this, Goodwillie (2014) introduced the concept of parenting with ‘protective vigilance’, a protective strategy used by parents of children with attention deficit hyperactivity disorder (ADHD) to safeguard them from harm through supervising them constantly. The strategy encompasses features of overprotection and enmeshment and was felt to be effective in managing children at risk from the symptoms of their condition. While the presentation of children with ADHD may be different to children with PPC needs, the concept of protective vigilance seems pertinent to describe the strategies used by participants in the current research when protecting their children. As opposed to an anxious, enmeshed attachment style, perhaps the notion of protective vigilance offers a more culturally acceptable, less pathological explanation to conceptualise this dependency.

For bereaved participants, continuing a strong attachment relationship with their child was just as important as for participants with living children. This fits with literature relating to continuing bonds (CB) (Klass et al. 1996) where it is thought that maintaining a bond with the deceased child and working towards resituating them, as opposed to the more traditional concept of ‘letting go’, is thought to be beneficial to the bereaved. There was a distinctive oscillation between states of heightened emotional distress and relief which signified separation anxiety corresponding to their early stage of grief and yearning for their child (Bowlby, 1973).

The longer term effects of child death and having a child with a life-limiting condition were noticed in terms of the overprotective and hypervigilant parenting of subsequent children. From conception and into subsequent children's lives, participants reflected anxiety about experiencing another child loss because the trust they previously had in the likelihood of a successful pregnancy had been broken. The two mothers who were pregnant during their participation in the current research managed their anxieties by 'emotionally cushioning' themselves through compartmentalising and avoiding the distressing emotions of the pregnancy for as long as possible (Côté-Arsenault & Donato, 2011). This was evident in their diary entries; difficult emotion was expressed more openly after they had attended reassuring medical appointments, and acknowledged less when they had no assurance of their child's health. This anxiety about the health of their child continued after birth, for example, Mandi reported a preoccupation with her baby's health which was managed through her anxious checking that she was still breathing and attendance for frequent medical check-ups. A paradoxical parenting style became evident for participants whereby their fear of further child illness or death created ambivalence in their response to their child. To protect themselves from further emotional pain they responded to their child with both distant aloofness and intense closeness (Warland et al., 2011). This paradoxical attachment relationship with subsequent children risked a number of immediate and longer-term difficulties. Duncan & Caughy (2009) introduce 'vulnerable child syndrome' which they defined as parental anxiety that a child may be at increased risk of dying despite their apparent health. This anxiety manifests within an over-compensatory parenting style and ambivalent attachment with the result that the child develops a number of behavioural problems.

Subsequent children were also idealised. Participants' with life-limited children perceived a need to compensate for the lack of time and energy they had to give them and often did this through intense feelings of guilt about not being able to meet their 'normal'

child's needs. Through experiencing their mother's stress at caring for their life-limited sibling, children risked feeling pressure to be the 'perfect' child who compensated their parent for their distress (Hugger, 2009). Such difficulties within the attachment relationship can have intergenerational effects that are likely to impact upon the mental health of future generations of children (Grout & Romanoff, 2000).

Another identified challenge within participants' attachment narrative was the exclusivity of the attachment relationship with their life-limited child which risked rejecting the wider family and drew attention to the traditional nature of the gender roles within these families. The current research was initially interested in the experiences of both men and women who had involvement in parenting children with life-limiting conditions. While recruiting participants was difficult, accessing fathers was not possible given the time constraints of the current research; it is unknown whether having more time may have led to more success in recruiting male participants. Macdonald et al. (2010) considered gender imbalance in the context of qualitative PPC research and identified that women formed 75 percent of the sample investigated in this arena. While this suggests that masculinity may not be easily compatible with the expectations of qualitative research, which requires significant self-disclosure and emotional expression, it also highlights that the role of men in this culture is to support the family financially. The demands placed upon them to earn money may mean that they are less available to take part in activities relating to the care of their child and family. This was reflected in fathers' limited use of hospice resources, such as the music group and other support groups, which drew attention to the possibility that hospices offer support services that may more effectively meet the needs of women than men. Because there have been limited opportunities for male voices to be heard through research, hospices cannot fully accommodate fathers needs which are likely to be just as great as the needs of mothers

due to the breadwinning pressures of their role and subsequent exclusion from relationships within their family.

### *5.3 A “Rollercoaster” of Emotion*

This theme highlights the level of resilience required of participants through exploring how they lived in anticipation of grief while also experiencing a sense of powerlessness when seeking help and compassion from others. It also considers how serendipitous and spiritual events can be empowering in building and maintaining resilience and hope.

Some of the experiences described by participants reflected negative and compassionless attitudes of others towards them. The experience of Joanne’s meeting with the commissioner, and removal of tokens of love from Mandi’s child’s grave indicated symptoms of compassion fatigue among these professionals. Rigid adherence to bureaucratic processes and a pervasive negative attitude towards those in need seemed to act as a way of retaining a sense of control for those dealing with death and illness within their profession. While this was not as immediately apparent in the context of hospice services, the perceptions relating to tokenistic service user (SU) involvement and unscheduled respite entitlement hinted that some staff within the hospice may have also been affected by symptoms of compassion fatigue (Beck, 2011). This was reinforced by the reflections of participants that staff further up the hierarchy within the hospice were more responsive to SU feedback than those working with them directly. It seemed that those who worked more directly with the trauma of these families lives were at risk of having less emotional resource available to respond to the needs of SUs. Such a phenomenon is common among professionals working within the human services and PPC is among the most emotionally demanding of these services because staff often work with families for extensive periods of time and develop strong relationships with them which come to an end after the child dies (Meadors et al., 2008).

In conceptualising how participants found resilience against the stresses of their role and compassionless responses of others, McCubbin and McCubbin (1993) offer a resiliency model of family stress, adjustment and adaption in relation to child illness. They found that where families encountered more stressors, had a negative appraisal of these stressors, more vulnerability factors, and fewer problem-solving, coping and resistance resources, they were at higher risk of stress and burnout. This fits with the messages from the current research. Occasions where emotional resilience was waning were apparent where participants: faced additional layers of complexity, such as their child's challenging behaviour or spousal illness; became physically unwell; approached an anniversary after their child's loss; experienced a sustained period of grief; had limited support in the care of their child and; less membership to a community of shared experience.

An adjunct to McCubbin and McCubbin's model might be Caldwell and Senter's (2013) perspective advocating for the strengthening of spiritual and religious resources in increasing resilience. Serendipity and faith were two central mechanisms facilitating hope among participants. Receiving support from the hospice to explore these elements enabled them to increase their resilience. It makes sense that given the contradictory nature of having a disabled child as both 'joy and sorrow' (Kearney & Griffin, 2001), supporting families to build resilience might be best achieved by enabling them to find ways to positively reappraise their circumstances as well as validate their distress (Graungaard et al., 2011).

#### *5.4 Transitioning Communities*

Belonging to a community underpinned all diaries. This became another strong resource to participants who perceived acceptance and shared experience. This community offered them internal support, compassion and understanding, and enabled them to provide support and help to others; a rewarding experience. Having a common goal, such as raising awareness of the hospice through fundraising activity, strengthened bonds within the community.



Participants felt misunderstood by communities they may previously have felt an allegiance to and had concerns about overwhelming them with their emotional conflict.

Within the hospice community, a strong collectivistic culture was conveyed where participants constructed their identity through an interdependent view of themselves. This was demonstrated by the frequent use of the words 'we' and 'us' indicating strong group cohesiveness (Pennington, 1986). This community was initially facilitated by the hospice but continued externally through other mediums, such as the parent Facebook page which provided an invaluable source of support to parents. Baum (2004) identified that internet parent support groups such as this are crucial resources for parents in managing stress and finding ways to cope and were particularly beneficial in facilitating stronger relationships with their life-limited child.

The concept of being accepted into one community and rejected by, or absconding from another, corresponds to Tajfel's (1979) social identity theory. Participants felt a stronger sense of belonging with those they perceived to share more common experiences. Committing to this community enabled them to form an 'in-group'. Activities such as the music group performances served to raise the status of the group, thus enabling it to resource itself with a sense of pride and satisfaction, an increased membership, less external rejection and increased funding.

Death and illness commonly evokes anxiety. An existential perspective might suggest that we manage our own anxieties about inevitable death by dissociating from, and denying it (Yalom, 2008). Participants were reluctant to share their experiences of death and illness outside the hospice community and sometimes even found it difficult to address within themselves. Much of the social rejection identified by participants may have been influenced by death anxiety. This notion is supported by participants who expressed that their own initial

perceptions of children's hospice were strongly associated with suffering, a message conveyed to the general public through media images of hospice. The public fear of death and illness has been heightened by the media who have saturated the public with decontextualized images and stories of tragedy and suffering in order to sell headlines (Moeller, 1999). The likely effect of this has been for the general public to protect themselves through developing a resistance to helping people who are suffering. Children's hospices use the media as a vehicle by which to fundraise and do so by conveying sympathy-evoking messages. The danger of reliance upon this strategy is that the PPC community may inspire awkwardness and resistance towards them which will further isolate them from wider society.

Anxiety associated with illness and death became evident within the organisational structure of the hospice and reflected through participants' commentaries on the controversial issue of integration within the hospice music group. Staff, bereaved and pre-bereaved families took part in the hospice music group which was felt to be a novel and beneficial forum by participants. The stage within the trajectory of palliative illness was deemed irrelevant to participants, yet they noticed there were no other forums within the hospice where bereaved and pre-bereaved families could integrate. They commented on the benefits of integration in this forum and expressed frustration about segregation, perceiving the hospice's ambivalence to enable integrated groups to be fragilising of them and preventative of a united identity. Perceiving the fragility of parents by the hospice may have been an anxious attempt to respond sensitively to the context of death, yet for participants, being perceived as fragile was in direct opposition to their desire to be superhumanly strong. Section 5.1 discusses the Superwoman cape as an omnipotent defence and demonstrates that through perceiving themselves in this way, participants felt better able to meet their child's needs without being constantly weighed down by the emotional load they carried. Through perceiving fragility, the hospice was felt to be disempowering of participants who aspired to

feel rewarded by their heroism and appreciated for their successful management of conflicting demands; instead they felt patronised. In analysing diaries and interviews for the current research, this argument was responded to by the researcher by integrating bereaved and pre-bereaved parents' data within the presented themes.

### *5.5 Clinical Implications*

A number of areas relating to service improvement were identified in the findings from the current research.

#### *i. Value service user participation*

Participants did not experience SU participation relating to the administration of services and commissioning decisions to be widely available. While forums for feedback were sometimes established, it was felt these did not value their expert position, often contained hidden agendas and limited their choice in forms of feedback. Services could advertise and encourage participation by their users and openly manage expectations from the start where resource constraints may not allow for all needs to be met. It will be important to ensure all relevant information is made available to SUs to inform their participation, even where this may give rise to controversy. Providing both anonymous and direct forums for feedback may encourage truer feedback.

#### *ii. Challenge negative perceptions*

Participants found opportunities to raise awareness of the hospice to be rewarding. Public and professional perceptions of children's hospices were considered to be inaccurate and heavily associated with death. Hospices are ideally situated to educate professionals involved with SUs through consultancy and training. Further integration with wider society could be encouraged through community awareness projects led by SUs. These might reflect the

creativity, joy and resourcefulness of the community rather than rely so heavily on sympathy-evoking methods geared towards fundraising and which risk public resistance.

*iii. Facilitate the establishment and integration of communities*

Community participation enriched SUs lives. Enabling the formation, development and integration of communities would be an efficient and effective use of resources. Services may choose to do this innovatively by offering to support parents to pool their knowledge and skills and support each other to meet child care needs, thereby enabling them to meet more of their own needs.

*iv. Ensure respite consistency*

Respite was valued as a central support structure for participants caring for life-limited children. The researcher was concerned at the limited sleep and rest participants received. Sleep loss poses a number of risks to our health and wellbeing; we should be particularly mindful of the risks presented to the children in the care of these exhausted adults. More consistently scheduled respite, planned earlier and allocated equally so that parents might have weekday, weekend and holiday respite breaks seems compulsory to meet their needs.

*v. Care coordinate and communicate*

There was a distinctive lack of care coordination reported by participants who took this responsibility on themselves and found that communication between services was limited. If support in this area is available, it went unreported across all diaries and interviews indicating that further resources in this area are desperately warranted.

## *5.6 Methodological Critique*

The sample size in the current research was large yet fell within the recommended guidelines for an IPA. The method adopted for interpreting the large amount of data was one of a number of options. A full IPA of the interviews may have been a more thorough method of

analysis yet for the purposes of the current research, this was not deemed feasible. Such a method may also have proven repetitive and resulted in the saturation of data for which a grounded theory method might have been more appropriate (Glaser & Strauss, 2009).

While recruitment took place across three hospice sites within the same organisation, seven of the submitted diaries were from one site. It is appreciated that SUs in the under-represented hospice sites may have had different experiences. The subordinate theme of Belonging and Shared Experience (Section 4.4) may have emerged from the analysis because of participants' membership to the hospice music group and the Facebook page; this may not be an emergent theme if participants who were not members of these forums had participated in the current research.

The demographic characteristics of the sample were largely similar consisting of white British women between the ages of 33 and 43. The sample was split between mothers who cared for children with life-limiting conditions and mothers whose infant had died after birth. While the sample was largely exclusive in this way, it did include participants with disabilities and diverse spiritual orientations. A sample including more cultural diversity may have represented different experiences and interpretations.

Due to the invisible nature of this SU population, the researcher actively engaged in the hospice community to inform the design of the research, to recruit a representative sample and to experience the community. While this presented a number of advantages to ensuring validity within interpretations, it may also have prevented objectivity within the analysis and deterred participants from sharing more intimate information about themselves, despite attempts to mitigate against this by assuring them of their anonymity within the research.

### *5.7 Research Implications*

While the current research offers an insight into the experiences of families accessing hospice services in the care of their child, it does not consider the perspective of families who are not accessing these services. Having an insight into those not receiving hospice input is likely to draw attention to perspectives that are unavailable to the current research and not adequately explored within the supporting literature.

Further research into the benefits of integrated interventions, such as the hospice music group, formed from staff, pre-bereaved and bereaved parents might offer evidentiary support to demonstrate the respective benefits of such a model. It may also offer further guidance to clinicians about how best to replicate and implement such interventions. Investigating the needs of families from ethnic minority backgrounds within this may shed light on why these families were not present within these groups (Davies, 2004). Finally, the current research focused on the experiences of mothers. Future research might investigate the experiences of fathers, access to which might be difficult. A participatory action approach to such research might be most feasible to accomplish such an endeavour.

### *5.8 Towards a Measure of Outcome*

A central aim of the current research was to contribute towards a specific measure of outcome for children's hospices to monitor the effectiveness of their services. It is recognised that such a measure may not accurately be generated from one qualitative research study and would require further investigation to inform a clinically useful, valid and reliable measure. In so doing, more extensive review of the literature in the area of PPC would be required, alongside further research conducted into staff, public and wider family perceptions of children's hospices. Research might gather data in a variety of ways using a mixture of qualitative and quantitative methods such as interviews, focus groups and psychometric measures, to ensure the weaknesses of different methods have been accounted for. Any

emerging items and subsequent measures should be tested for reliability. From the current thesis, several relevant areas emerged and could be usefully included in any future measure of outcome. Some of these include:

- How children's hospices manage issues relating to inclusion, culture, spirituality and religion;
- The way in which families accessed children's hospices. Items may consider whether they were given accurate information about the hospice in advance, whether their expectations of the available services were well managed and whether they were given choices over things such as timing of access, the services available to them and the geographical location of the hospice;
- What opportunities they were given to influence both the care package they received and the wider functioning of the hospice. Items may address whether they felt the hospice valued their feedback and how they knew that it made a meaningful change to hospice services;
- The hospice's support of their membership to support groups by enabling opportunities to form relationships with families at all stages of the palliative care trajectory;
- The extent to which families felt their respite entitlement was allocated fairly and in an organised, consistent and useful way;
- The extent to which families felt the hospice communicated with other services related to the health care needs of their child and facilitated 'joined-up' and collaborative care.

While a number of common areas have been highlighted through the current research, particular attention should be given to the individuality of each family accessing hospice services. In achieving this, it is suggested that any measure of outcome allows for families

to generate some of their own items by which outcomes can be monitored (Alves et al., 2013).

### *5.9 Conclusion*

The current research found that mothers of children with life-limiting conditions, both bereaved and pre-bereaved, demonstrated resilience despite being required to manage a number of conflicting demands, often without adequate professional support. Despite fighting to demonstrate their deservedness in accessing resources, they perceived many of the needs they identified to be misunderstood by services and wider society. In finding ways to cope and motivate themselves to manage multiple stresses, participants: engulfed themselves in their tasks through close identification with their multiple roles; used heroism as an omnipotent defence in shielding against their own feelings of distress and internal conflict; formed an enmeshed attachment their life-limited child and parented with protective vigilance; built hope through challenging negative appraisals of their situation by noticing serendipitous and spiritual events and; created communities with other parents sharing similar experiences and who worked together to raise awareness of their community.



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## Critical Appraisal

### 1. Introduction

Within this critical appraisal I will outline the trajectory of the research project including how I came to choose the topic, the problems I encountered with recruiting my sample and the challenges of writing it up. I will explore the project's strengths and weaknesses, with consideration given to the wider implications of these. This appraisal will be informed by the research journal I completed during the course of the research and in which I recorded my progress and reflections. I will also reflect on what will be important to remember in any future research I conduct along with any learning points and how these have shaped my personal and professional development.

### 2. Choice of Research Topic

Before training to become a clinical psychologist, I worked as Research and Development Manager for an NHS Trust in the Midlands. This role led me to meet a number of clinicians across the country specialising in different fields of healthcare, one of these was a Consultant Paediatrician with an interest in child development within paediatric palliative care (PPC). He provided me with several opportunities to work with children and their families struggling with developmental and palliative care needs which inspired my initial psychological interest in the area. At this time, I also had a close friend working as a manager in the children's hospice I recruited my sample from. Contrary to my expectations, conversations with her demonstrated that working in PPC facilitated her adversarial growth<sup>7</sup> beyond the stress and risk of compassion fatigue she faced. I also struck by the hidden nature of the population

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<sup>7</sup> Adversarial growth is a concept derived from the perspective that when directly exposed to the trauma of others, it is possible for a professional to develop and grow. These constructs may act to safeguard individuals from the negative emotional states of burnout and compassion fatigue. (Joseph & Linley, 2008).

accessing PPC services as it seemed to me that these families were largely invisible outside publicised fundraising events, such as Comic Relief.

### *2.1 Volunteer Experiences*

Several other serendipitous opportunities contributed to my interest in PPC. Having worked in a voluntary capacity for Comic Relief taking donations, for ChildLine as a telephone counsellor, and as Governor for my local primary school, I was introduced to some of the difficulties families caring for children with PPC needs encountered.

Comic Relief raised my awareness to our society's culture of guilt in relation to the PPC population. The public called in to donate following the broadcasting of an emotional plea for donations to fund hospices. They were often extremely upset, explaining how difficult they found the experience of watching the hardship of families caring for life-limited children. I recall one particular donator expressing his frustration about 'having to watch such awful things on the telly'. Being given an insight into these families' struggles presented him with feelings he struggled to tolerate. It interested me that donations were sometimes given to alleviate guilt.

This message was reinforced by my experience as a school governor. On taking up the role, the school was being built and the tasks of the Governing Board were to: consider architectural design issues; employ teaching staff; agree a school ethos and; consider applications from the families of local children hoping to attend. Having received an application from a family with a child struggling with a chronic illness, the Board expressed anxiety about being able to meet this child's needs at such an early stage in the school's development. A number of protests were presented including that the design of the school may not be appropriate for wheelchair access and that the staff may be insufficiently trained to meet the requirements of this child. I found these arguments negligible given that the

school was still in the early design stages and staffing issues could be held in mind as completion of the building and recruitment took place. My observation was that managing disability and illness was an anxiety-provoking concept for the Board. This reinforced the impressions I gained from working for Comic Relief.

In taking calls for ChildLine I received several calls from young people who were grieving chronic illness, or the anticipated end of their life following terminal diagnoses. They talked about feeling alone and having no one to discuss their feelings with because they did not want to further distress their families. They worried about their parents and felt guilty that they were the cause of their parents' pain. Conflict between accepting death and receiving further treatment was an ever-present issue on their family's agenda. Often these children held different perspectives to their parents, preferring not to continue with intrusive treatment regimens but being afraid to articulate this.

These three experiences gained me an initial insight into the complex web of emotional difficulties these families faced. I was interested in the societal responses to illness and death that seemed to affect these children's short lives so profoundly. Rarely were services fully available to them, and those that were, were insufficiently funded; even the responses of the extended family seemed fearful and avoidant. These dynamics raised my awareness and inspired my interest in the area.

## *2.2 Paucity of Previous Research and Feasibility*

I was particularly motivated to ensure that the findings of my research be a useful adjunct to the PPC evidence base. I initially made contact with three hospice organisations to discuss the feasibility of a project in PPC. One organisation indicated that research directly involving children that accessed their services would be difficult because they generally encountered significant difficulties in communication. The second hospice organisation provided me with



a copy of their Research Strategy setting out areas of interest they would be keen to support. The third organisation was especially keen to consider the reasons some families did not access hospice services and what some of the barriers to access might be.

Having considered the Research Strategy I had been provided, my attention was drawn to the concept of exploring family experiences of children's hospices; an idea present on the agenda of two of the hospice organisations I had spoken with. An initial literature search scoping for the availability of research relating to family experiences of children's hospices demonstrated a surprising paucity of evidence. There was also a paucity of general literature exploring experiences of being a family with a child with a life-limiting or life-threatening condition. Much of the available literature tended to be practice-based and published within books on PPC, written from the perspective of one author, or based on a single case report. This evidence highlighted the multitude of stressors these families encounter and the potential for burnout and psychological distress. The Research Strategy also identified a need to measure the outcomes of children's hospice services. I felt a key role of a clinical psychologist working within a children's hospice might be to evaluate the interventions offered by the hospice and consider how to develop services in line with user need.

In meeting the needs of the third hospice, I elected to use the requirement to conduct a literature review to consider access to children's hospice services. The aim of the review was to collate the findings from some of the available evidence and present a concise picture of the current challenges families experience in accessing children's hospice services.

### 3. Selection of Research Methodology

Having recognised I was interested in exploring the experiences of families accessing children's hospice services, the choice to use qualitative methods to do this seemed most

appropriate. Having an insight into the perceptions and understandings of participants using a method enabling me to interpret their meanings was especially attractive to me. I was aware of the potential difficulty that may be posed by recruiting from a population that was largely hidden and faced a number of conflicting demands on their time (Tomlinson et al., 2007). Qualitative methods allow for an in-depth investigation of participants data thus requiring a smaller sample (Smith et al. 2012). In light of this, it seemed that the most appropriate method to meet these objectives would be an interpretative phenomenological analysis (IPA) as this method enabled me to interpret participants' subjective meanings and immerse myself in a smaller sample's data.

I chose to recruit parents of children with life-limiting and life-threatening conditions as it seemed to me that parents would have a holistic overview of the family's needs which would enable the richest data. They were also more likely to be able to engage with a diary method which I was especially motivated to use. The limited published literature in the area using qualitative methods tended to make use of interviews (Contro et al. 2002; Kirk & Pritchard, 2002). Interviews provide a retrospective account of experience and are likely to be influenced by external variables and distorted over time. While I felt this would be useful to enable me to perceive the meanings participants made of these experiences over time, I wanted to capture experiences as they happened. Keeping a diary seemed like a useful method to capture the 'in-the-moment' perspective (Bolger et al. 2002; Iida et al. 2003). Conversations with my research supervisor and staff members from the hospice organisations I had initially liaised with indicated that one diary entry per week over a 12-week period would be feasible within the confines of a doctoral-level project.

A pilot of the research method was conducted on my first participant. I recognised that, due to conflicting demands on their time, I would need to send participants regular reminders inviting them to complete an entry. I also followed up with them half-way through

the process of the research to ensure they felt supported. In order to ensure as many areas as possible were included in the research an interview element was included to validate and expand on the information provided in the diaries. This also served a precautionary function in the event that diaries did not provide enough data for interpretation.

#### 4. Recruitment

During the feasibility and design stages of the research, three different hospice organisations in the Midlands expressed interest in participating in the project.

##### *4.1 Ethical and Governance Approval*

Having spent several years previous to commencing the doctorate in clinical psychology working in healthcare research, I anticipated the process of applying for a favourable opinion through the National Research Ethics Service to be lengthy and complicated. However, I was pleasantly surprised, and experienced the process of gaining a favourable opinion and submitting a substantial amendment to be relatively smooth and supportive. There were some minor complications, such as the requirement to use their standardised Informed Consent Form rather than the one I had drafted, but this was managed at an early stage. I found the advice of the panel generally helpful and their approach to my research was warm. I was interested to observe that my application required the consideration of 12 or more members which felt somewhat disproportionate to the scope of the project.

There were two things I found less helpful in the advice I was given. The first was to replace my use of the terms ‘life-limited’ and ‘life-threatened’ with ‘sick’, ‘ill’ or ‘unwell’ in my participant correspondence. While appreciating this advice was given with the intention of ensuring my research was as person-centred as possible, it demonstrated that the panel did not have an insight into the culture I would be recruiting my sample from. The suggested alternatives seemed reductionist to me, as these children were not merely sick or unwell.

Mothers of life-limited children are, in essence, trained medical professionals in their child's care. They spend time being trained by medical experts to learn how to deliver a number of complicated medical interventions to their children and are well-versed in the terminology used by PPC services. This terminology has been specifically devised by PPC organisations, such as Together for Short Lives, to ensure it is as clear, sensitive and useful as possible to all people involved in a child's care.

The second piece of advice was to write to participants' General Practitioners to inform them that their patient would be taking part in the research. Throughout the research process participants communicated their frustration that others fragilised them; an issue that also emerged in the way the hospice segregated bereaved and non-bereaved parents. Participants were frustrated at the expectation of services that they should resiliently tackle a number of conflicting demands requiring them to make many personal sacrifices. At the same time, they felt their resilience went unacknowledged when it came to less significant things such as taking part in this research. This conflict became more apparent within the research, emerging within the theme of "Must get my Superwoman cape on".

#### *4.2 Impact of Time*

As this was a doctoral research project, the progress of the research design and implementation was slow due to a number of other competing demands. This meant that between the feasibility stages and the start of recruitment, one of the hospice organisations who had initially indicated a commitment to the project lost interest and instead committed to an in-house research project. I found this disheartening having taken their initially enthusiastic expression of interest at face value.

The other two hospice organisations continued to participate and supported me by encouraging parents to make contact with me directly and through sending parents letters

enclosing the relevant participant information. Only one parent responded in the first five months of recruitment. While this enabled me to pilot the research process on the first participant, I became more aware that this community was even more unavailable than I had initially perceived. I became quite concerned that my plans to recruit might prove fruitless and the project may not meet the required deadline.

Having experienced similar responses in my previous research role, I considered how I had overcome this challenge before. I first managed my expectations by recognising that I could complete the research with a minimum of four participants if necessary which meant the project felt more manageable. One hospice newsletter advertised several musical events which demonstrated to me the creative culture of this organisation and meant that, as a singer, I might have something to offer. I contacted the music therapist at one of the hospice organisations and asked whether there were any music forums I could help with. In my past experience, having a presence within the community I was trying to recruit from enabled me to form a rapport with service users and presented an excellent opportunity to engage them directly. I was invited to join a hospice music group which led to my participation in one of their public performances. Following this were a number of subsequent performances and events that the group participated in and to which I was invited to take part.

Due to the problems with recruitment, six of the participants in the current research also attended the music group within one hospice site to varying degrees. As a result of this, it is appreciated that participants from the under-represented hospice sites may have had different experiences. The subordinate theme of Belonging and Shared Experience may have emerged from the analysis because of participants' membership to the hospice music group and the Facebook page; this may not be an emergent theme if participants who were not members of these forums had participated in the current research.

### *4.3 The Emotional Consequences of Engagement*

While my active engagement enabled me instant access to mothers who were willing to take part in my research, it also made me directly aware of the extent of the difficulties these families encountered. Because of this I felt my contribution held more importance as it was a way of giving back to the hospice.

The design of my research was tailored to ensure participants were supported by regular contact with me; this weekly contact resulted in an ambivalent sense of acceptance into their community. While I felt welcome by the hospice, I also felt like an imposture fraudulently seeking data for a research project that would invariably facilitate my professional development.

The weekly email and text reminders I sent were usually responded to by parents enquiring about how I was and offering me details about the next music group. I was sent invitations to hospice events and received some photographs of their hospice adventures. The nature of the reflective diary method often meant that the entries were written directly to me and these communicated very distressing thoughts and feelings about their experiences on a weekly basis. In two interviews, parents became so upset that I stopped the interview and agreed to return another time when circumstances felt more manageable for them. I felt pressure to replicate the resilience they modelled to me in my own life and because of the ‘Superwoman’ capabilities these participants were keen to convey, I was alerted to my own sense of inadequacy by comparison.

The emotional consequences of this research are important to reflect on because I did not anticipate them in advance of commencing the research. Being prepared for what now seems an obvious risk may have pushed me to use research supervision in a different way. I

might have asked for a more frequent arrangement and asked to address this aspect rather than maintaining a sole focus on the research process.

My response to engaging with this community facilitated my understanding of the subordinate theme “The Elephant in the Room: Death, Dying and Disability” that emerged from my research findings. These emotions are complex and difficult to experience; given a choice I believe many would choose to avoid them. Using observational skills (Hinshelwood & Skogstad, 2002) and my emotional responses to support my interpretation of the participants’ data served as a useful barometer.

## 5. Gathering Data

### *5.1 Diaries*

On taking informed consent, participants were provided with a Diary Preface which set out the aims for the diary and offered an example entry written by a member of staff working at a children’s hospice. It was difficult to know what constituted sufficient instruction because, while the research aimed to consider participants’ wider experiences of having a life-limited child, it was also interested in their experiences of hospice which may not have been commented on if it had not been guided. The Diary Preface was agreed with my research supervisor as achieving the right balance and participants reported feeling clear about the research aims having read it. Nine participants wrote diaries for the research; one of these decided not to continue her participation and chose not to respond to communication from me. I continue to be concerned about what caused her to passively withdraw from the research. Without feedback, I have struggled to know what I could have done differently to support her to continue or actively withdraw from the research.

Managing the diaries was time-consuming and difficult. It required me to be available every Friday during the course of eight months to send reminder emails and texts to participants as per their preferred method. Often I would receive entries throughout the week via email which I would have to print out and file safely while ensuring the electronic file was password protected. For those writing paper diaries, I could never be sure the entries were being kept and I had to wait patiently to collect them before I could ascertain how many entries there would be and of what type and length. The transcribed audio-recorded diary also had a different structure to the written diaries because of the differences between the spoken and written word. The effects of different methods for writing the diaries were not apparent as I had expected them to be and all diaries conveyed interpretable messages. I was surprised by the length and detail within the entries. They demonstrated trust and commitment through their honest content.

## *5.2 Interviews*

Interviews were held with only six of the eight participants; two were unavailable to take part in the interview. While diaries were subject to a full interpretative phenomenological analysis, interview transcripts were read and re-read and on the second reading passages corresponding to or conflicting with the diary were highlighted and used to confirm, clarify or disqualify my initial interpretations.

It was very difficult and time-consuming to interview these mothers because of the background noise and distractions that were presented by their children. I was conscious that I needed to provide the correct paperwork, try and standardise my methods, ask questions and respond sensitively while entertaining young children who saw my handbag as an adventure to be explored. I learned to prepare for interviews by taking all valuable and sharp things out of my bag in advance and leaving important paperwork in the car. I began to appreciate the



importance of infection control, removing my shoes and using antibacterial gel before going into participants' houses.

Harder to manage were the children who were not able to make distractions; instead sitting solitarily in their chair, paralysed. I found myself trying not to replicate the difficulties these parents had echoed in their diaries about visitors not engaging with their child but it was difficult without receiving a response. I felt humbled by these children, perhaps humbled into silence which made it difficult for me to interact with them. I was concerned I might 'break' them, or intrude upon their space if I were to make physical contact with them; something as a trainee clinical psychologist, I would not usually be tempted to do, yet I felt it was necessary with these children. Perhaps touch was a natural inclination given the extent of their sensory impairments. I often became frustrated with myself for not knowing what would be most effective. I could understand the awkwardness of others that participants commented on in their diaries through my own experience.

### *5.3 Transcription*

Due to the volume of data that was gathered, all interviews were transcribed by professional transcribers along with the audio-recorded diary. I typed up the written diaries myself and checked the transcribed diaries for accuracy. This process enabled me to listen to the interview for its content rather than being preoccupied with typing.

Having used one transcriber for the pilot participant's diary and interview, I chose to find an alternative transcriber for the other interviews as I was frustrated with the inaccuracy of the initial piece of work; for which I felt I had been excessively charged. The first transcriber had been suggested by the course which made it difficult to manage. On reflection, I should have requested references and contracted directly with the transcriber before using them. My frustration at the inaccuracy of the transcripts alerted me to the feeling of protection I held

over my participants' data. I felt a strong sense of gratitude for their participation; the notion that their efforts may not have been accurately transcribed symbolised a lack of respect for their time and trust in me. I learned to be more careful when locating the second transcriber and clearly indicated my expectations in advance of providing the data.

## 6. Data Analysis

Having only once before experimented with an interpretative phenomenological analysis (IPA), I was ambivalent about how many risks to take and how interpretive I could be with my participants' data. While I felt quietly confident that I could interpret the data with a degree of accuracy because of the extent of my involvement in my participants' worlds over the previous six months and my enthusiasm to ensure I did the data justice.

A dialectic presented itself during write-up of the analysis. I found myself erring towards safer interpretations despite being tempted to engage with a number of deeper levels. Supervision was an important part of this process to ensure I was achieving some balance between the two camps. Despite my use of supervision, this issue was a central topic of discussion within my research viva meeting and the recommendation of both examiners was to engage at a deeper level with the analysis. It is possible that my regular contact with participants and participation in hospice forums, such as the music group, facilitated my immersion in the hospice's norms, values and culture. To some extent this immersion may have made it difficult to objectively engage with a deeper psychological interpretation which became easier after a period of distance from the hospice during the write-up of the research. In light of this possibility, involvement in the hospice community had both advantages and disadvantages for the context of qualitative research; it enabled a strong empathy and identification with the participants but also prevented researcher objectivity.

Most resonant to me were the effects of being a carer to a relative accessing end-of-life care services, as well as a researcher in the context of this research. My strong identification with these participants and the deeper interpretations I have discussed around caregiving, death and illness made it very difficult for me to consider the data at this level without the time to create space between the hospice community and my involvement with participants.

In addition to this, the process of analysing the data was massively time-consuming, as one might expect it to be. I was aware that I had a particularly large sample and a large amount of data for the remit of a doctoral-level IPA project. In this way I set a difficult task for myself. I felt obliged and determined to use all the data because of what it had taken my participants to give it. While I explored the option of excluding the interviews or two of the diaries, I chose to commit my time to incorporating it all.

## 7. Personal and Professional Development

### *7.1 Managing Relationships*

A number of personal challenges were posed by this research. Being able to manage relationships with participants that did not become too personal, too therapeutic or too aloof was difficult. It was especially difficult to manage the individual differences of relationships within this.

Katie, for example, invited me to contribute to a number of memory-making projects she had been working on since the death of her child. She gave me the product of one of her creative projects as a gift after our final research meeting and explained that she wanted me to have it as it had been a central part of her diary narrative. I felt conflicted about this and unprepared for such a gesture. I managed it through acknowledging how thoughtful it was of her to gift me something so special while also asking her to let me give a donation to the

hospice for it. I was confident that the material value of the gift was not high, yet was concerned that I was unsure of my employer's policy on accepting gifts. I was also aware that not to have accepted it would have been directly rejecting of her expressed desire to continue the bond with her child through the research. Supervision helped me recognise that accepting the gift was a reasonable response and in conceptualising my feelings, I might consider how affected I choose to be by bureaucratic processes that can sometimes deter us from responding appropriately to the context.

### *7.2 Finding Resilience*

While I had anticipated high levels of stress in conducting this research, I had not understood the extent of worry that struggling to recruit participants would pose. I was disappointed in myself having selected a difficult population to recruit from as I had presumed that, given my previous research experience, I would find a way to recruit to this project.

I learned that sometimes stress motivates. In this example, it forced me to be proactive and to find a way in that not only helped me recruit to my research but changed the way I viewed my training to become a clinical psychologist. I was inspired by my participants, and by the music therapist who helped me in my endeavours. I remembered the real reasons that clinical psychology had been my chosen profession and will try to return to this notion when I am struggling to locate my own resilience in the future.

## **8. Lessons for Conducting Research**

I found my previous experience of conducting research in healthcare useful as it helped me to manage my expectations and employ project management skills. The project also gained me an insight into qualitative analysis, an area I had not engaged in outside of previous postgraduate training, service evaluation and audit experiences from my previous research role.

There were a number of lessons I learned that have inspired recommendations for any future research I might conduct:

- Recruiting to research is a much simpler process when working within the service you are recruiting from. If working outside the service, finding a way to participate and not solely relying on others to locate participants is likely to be most effective;
- Never get complacent about engagement, always continue frequent contact with those who show an interest;
- Contract assertively with all who may be involved in the research from the start so all expectations are managed;
- Always have a planned timeline yet leave twice the time you anticipate any activity to take;
- Be aware of the emotional consequences of interpreting data gathered from a service with which you have close involvement, and which may present issues that you might identify with strongly;
- Anticipate dilemmas in advance and familiarise yourself with the policies and procedures of the organisation in which you are working.

## 9. Final Comments

Undertaking this research has been both the most difficult project I have participated in and the most rewarding. It has challenged my perspective of what we can expect of others in terms of coping and resilience and has given me first-hand experience of how people can cope with the most difficult experiences and bounce back given the right conditions.

Perhaps the most significant message this project drew my attention to was the extent of the segregation between and within healthcare services. Despite our frequent use of terms such as ‘collaboration’, ‘coordination’, ‘joined-up care’ and ‘working together’, we could

practice this more. Clinical psychologists are trained to communicate and to break down barriers to effective communication. My experience in my previous research capacity, and in this research, is that access to clinical psychologists as a resource is difficult; they themselves can be a hidden community, particularly within the research arena. In noticing this, I appreciate the importance of continuing to engage in research and commit to expanding the evidence base to improve services wherever possible.

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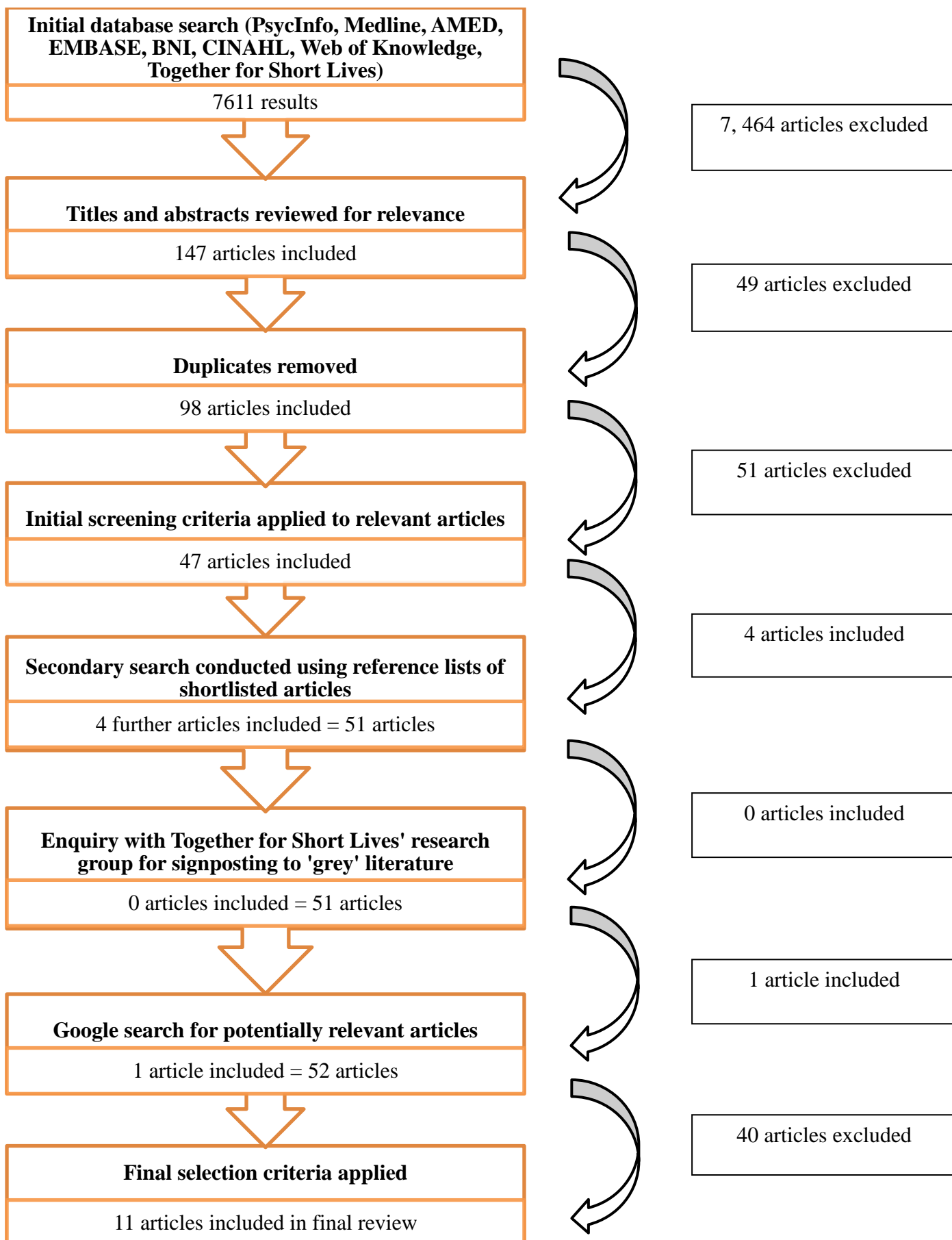


Appendix A: Table of Search Terms Used in the Literature Review

Search Term List 1`	Search Term List 2	Search Term List 3
Access*	“Long term ventilat*”	Child*
Barrier*	Disab*	Infant*
Refer*	“End of life”	Baby*
Gatekeep*	“Life limit*”	Babies*
Restrict*	Cancer*	Neonat*
Refuse*	Oncolog*	“Young people”
Choice*	Leukaemi*	“Young person”
Use*	“Life threaten*”	Adolescent*
Decision*	“Complex need*”	Famil*
Decid*	“Technology depend*”	Parent*
Consider*	Dying	Mother*
Perception*	“Short break”	Father*
Perceiv*	Respite*	Sibling*
Concern*	Hospice*	Mum*
Problem*	Palliative	Dad*
Meaning*	“Community service”	Brother*
Enrol*		Sister*
Availab*		Paediat*
Factor*		Pediat*

\*Indicates truncated search terms

## Appendix B: Flow Chart of Literature Search Process and Selection of Articles for Review



Appendix C: Table of Methodological Features for Literature Review

Methodological Feature	Article Number												
	1	2	3	4	5	6	7	8	9	10	11	12	Articles with full score
Rationale, objectives and hypotheses clearly stated?	2	1	1	1	1	1	2	1	1	1	1	1	2
Details of method and design given?	2	2	2	2	2	1	1	2	2	1	1	1	7
Details of sample demographics given?	2	2	2	2	2	2	2	1	1	2	2	2	10
Representiveness of sample stated?	0	0	1	1	1	1	0	0	1	1	0	0	0
Reliability of measures tested/reported?	0	0	1	0	0	0	0	0	0	0	0	0	0
Validity of measures tested/reported?	2	0	1	0	0	0	0	0	0	0	0	0	1
Missing data acknowledged and explained?	1	2	2	1	0	0	1	1	1	1	1	0	2
Significance levels/confidence intervals provided for results?	2	2	2	2	2	1	1	0	2	2	0	2	8
Effect size calculated and clearly reported?	1	0	0	0	0	0	1	0	0	0	0	0	0
All study questions/hypotheses answered in results?	2	2	2	2	2	2	2	2	2	2	2	2	12
All limitations of study acknowledged?	1	1	2	1	1	2	1	1	1	1	1	1	2
Generalizability of study considered?	0	2	0	1	1	2	2	0	1	1	2	1	4
Total Score / 24	16	14	16	13	12	12	13	8	12	12	10	10	

# Appendix D: Summary of Articles Included in the Literature Review

<i>ID Code</i>	<i>Authors and Publication Date</i>	<i>Title</i>	<i>Country</i>	<i>Method and design</i>	<i>Sample Size (n)</i>	<i>Key Findings</i>
<b>1</b>	Chang, MacLeod & Drake, 2013	Characteristics influencing location of death for children with life-limiting illness	New Zealand	Case series study	494 children	<ul style="list-style-type: none"> <li>• Children from an ethnic minority background are more likely than Caucasian children to die in hospital</li> <li>• Children with a cancer diagnosis were significantly less likely to die in hospital than those with non-malignant disease</li> <li>• Children with a referral to palliative care (PPC) were less likely to die in hospital</li> <li>• Infants were more likely to die in hospital than older children</li> </ul>
<b>2</b>	Davies, Sehring, Partridge, Cooper, Hughes, Philip, Amidi-Nouri & Kramer, 2008	Barriers to palliative care for children: Perceptions of pediatric health care providers	USA	Cross-sectional study	240 (117 nurses, 81 physicians)	<ul style="list-style-type: none"> <li>• Four main barriers: Uncertain prognosis; family unable to acknowledge incurable condition; language barriers and; time constraints</li> <li>• Eight secondary barriers associated with communication and lack of education in pain and PPC were identified</li> <li>• There were differences between physician and nurses' perceptions of the central barriers</li> <li>• There were differences between intensive-care and non-intensive care staff perceptions of central barriers</li> </ul>
<b>3</b>	Keele, Keenan, Sheetz & Bratton, 2013	Differences in characteristics of dying children who receive and do not receive palliative care	USA	Retrospective cohort study	24342 children (919 received PPC, 23,423 did not receive PPC)	<ul style="list-style-type: none"> <li>• Most patients who died in hospital did not have documented receipt of PPC</li> <li>• Children receiving PPC received fewer invasive procedures (i.e. medications, mechanical ventilation, parenteral nutrition)</li> <li>• Older age increased the chances of receiving PPC</li> <li>• African-American children received significantly less</li> </ul>

						PPC than Caucasian children <ul style="list-style-type: none"> <li>• Children who received PPC were significantly more likely to be insured privately</li> <li>• Receipt of PPC varied significantly by diagnostic category. Most commonly in receipt of PPC services were children with central nervous system diseases and malignancies</li> <li>• Involvement with PPC services was related to fewer intensive-care admissions</li> </ul>
4	Knapp, Madden, Wang, Kassing, Curtis, Sloyer & Shenkman, 2009	Effect of a pediatric palliative care program on nurses' referral preferences	USA	Cross-sectional study	279 nurses (141 working in a PPC program unit, 138 not working in a PPC program unit)	<ul style="list-style-type: none"> <li>• Few significant differences exist in nurses' preferences as to whether or not to refer to PPC</li> <li>• Nurses working for PPC program sites were 3.7 to 10.4 times more likely to refer to prior to an end-of-life diagnosis</li> <li>• Overall, fewer nurses would refer for diabetes</li> <li>• All nurses would refer for cancer diagnoses prior to end-of-life</li> <li>• More nurses from PPC program sites would refer for progressive conditions prior to end-of-life</li> <li>• Nurses from ethnic minorities were less likely to refer to PPC for certain diagnoses prior to end-of-life</li> <li>• Formal training was associated with earlier referral</li> </ul>
5	Knapp, Madden, Wang, Kassing, Curtis, Sloyer & Shenkman, 2011	Pediatric nurses' attitudes toward hospice and paediatric palliative care	USA	Cross-sectional study	279 nurses (141 working in a PPC program unit, 138 not working in a PPC program unit)	<ul style="list-style-type: none"> <li>• Nurses from PPC program sites had more positive attitudinal scores towards PPC and hospice</li> <li>• Those who received formal training in PPC had higher positive attitude scores towards PPC and hospice</li> </ul>

6	Knapp, Thompson, Madden & Shenkman, 2009	Paediatricians' perceptions on referrals to paediatric palliative care	USA	Cross-sectional study	303 paediatricians	<ul style="list-style-type: none"> <li>• More likely to refer to PPC prior to the end-of-life were: <ul style="list-style-type: none"> <li>- Paediatricians from an academic practice setting</li> <li>- Paediatricians with more 'Medicaid' patients on their caseload</li> </ul> </li> <li>• Less likely to refer to PPC prior to the end-of-life were: <ul style="list-style-type: none"> <li>- Hispanic paediatricians</li> <li>- More experienced paediatricians</li> <li>- Paediatricians who practice in a hospital setting</li> </ul> </li> <li>• More years in practice was associated with decreased odds of referral prior to end-of-life</li> </ul>
7	Lindley, Mark, Lee, Domino, Song & Vann, 2013	Factors associated with the provision of hospice care for children	USA	Case series study	311 hospices (1368 hospice observations)	<ul style="list-style-type: none"> <li>• Professional membership increased probability of offering hospice services</li> <li>• Small and medium sized hospices were less likely to provide care to children</li> <li>• Competition in the previous year diminished the chances of offering hospice care for children</li> </ul>
8	Siden, Miller, Straatman, Omesi, Tucker & Collins, 2008	A report on location of death in paediatric palliative care between home, hospice and hospital, 2008	UK, Australia & Canada	Case series study	703 children (318 from the UK, 233 from Australia & 152 from Canada)	<ul style="list-style-type: none"> <li>• Location of death significantly varies by diagnosis <ul style="list-style-type: none"> <li>- Children with cancer and metabolic or biochemical conditions were most likely to die at home or in paediatric hospice</li> <li>- Children with CNS, neuromuscular, chromosomal, multi-organ or cardiopulmonary conditions were most likely to die in hospital</li> </ul> </li> <li>• Overall, there was an even distribution of death at home, hospital or hospice</li> <li>• In Canadian facility children were most likely to die in hospice, in the UK facility children were most likely to die at home or in hospital equally, and in Australia children were most likely to die at home.</li> </ul>

<b>9</b>	Thompson, Knapp, Madden & Shenkman, 2009	Pediatricians' perceptions of and preferred timing for pediatric palliative care	USA	Cross-sectional study	303 paediatricians	<ul style="list-style-type: none"> <li>• Paediatricians were divided in their definitions of PPC, most suggesting it was the same as hospice care, defined it incorrectly or did not know how to define it</li> <li>• Less than half of paediatricians had referred to PPC</li> <li>• Almost a third did not know whether local PPC services existed</li> <li>• There was no consensus as to timing of referrals regardless of disease diagnosis</li> <li>• There was no association between the definition of PPC and having made a referral</li> </ul>
<b>10</b>	Vadeboncoer, Splinter, Rattray, Johnston & Coulombe, 2010	A paediatric palliative care programme in development: trends in referral and location of death	Canada	Case series study	341 children (189 who died during the study period)	<ul style="list-style-type: none"> <li>• There was an increase in referral for all diagnostic categories over the study period</li> <li>• There was an increase in referral from all referral sources over the study period <ul style="list-style-type: none"> <li>- There was a particular increase in referral from neurology and paediatric and neonatal ICUs</li> </ul> </li> <li>• The PPC programme grew during the study period and increased referrals corresponded to growth (i.e. opening of new hospice resource)</li> <li>• Most children died in hospital followed by home and then hospice</li> <li>• The number of deaths in hospital in which PPC were involved has increased over time</li> </ul>
<b>11</b>	Verela, Deal, Hanson, Blatt, Gold & Dellon, 2012	Barriers to hospice for children as perceived by hospice organisations in North Carolina	USA	Cross-sectional study	61 hospice organisations (26 providing paediatric hospice care)	<ul style="list-style-type: none"> <li>• Hospices serving children differed from hospices not serving children in their perception of barriers</li> <li>• Different hospices provided different services including: hospice care at home, inpatient hospice care, pastoral care, respite care, bereavement services &amp; interpreter services</li> <li>• A higher number of hospices serving children also offer</li> </ul>

						<p>more services</p> <ul style="list-style-type: none"> <li>• Barriers perceived by hospices serving children included (in order of importance): <ul style="list-style-type: none"> <li>- Lack of paediatric referrals</li> <li>- Families wanting to continue curative therapies</li> <li>- Complexity of children's care needs</li> <li>- Lack of paediatric trained personnel</li> <li>- Lack of paediatric consultation</li> <li>- Lack of certainty re. prognosis</li> <li>- Language barriers</li> </ul> </li> <li>• Barriers perceived by hospices not serving children included (in order of importance): <ul style="list-style-type: none"> <li>- Lack of trained staff</li> <li>- Inconsistent paediatrician and hospice plan of care</li> <li>- Lack of staff trained to provide paediatric care</li> <li>- Lack of paediatric pharmacy services</li> <li>- Lack of paediatric consultation</li> </ul> </li> </ul>
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## Appendix E: Recruitment of Participants for the Research

The researcher met with one hospice organisation and agreed strategies for recruitment. Participants were identified from across two hospices within this organisation. Letters were sent to parents to invite them to express their interest in taking part enclosing the Participant Information Form (PIF) (Appendix F) and Consent to Contact Form (Appendix G). The researcher also identified suitable parents through her participation in a hospice-led music therapy group. An informed consent meeting was arranged during which the researcher explained the process of the research, answered questions, took informed consent (Appendix H) and provided the relevant materials for participation.

The first participant piloted the proposed methodology. While the methodology for subsequent participants remained the same, it was identified at pilot stage that the debriefing meeting could take the form of a semi-structured interview using a topic guide (Appendix I). The aim of including an interview was to capture retrospective reflections and increase ‘trustworthiness’ of the findings through further validation (Morrow, 2005).

Participants were asked to complete a minimum of 12 reflective diary entries over three months focusing on their experiences of parenting a child with a life-limiting condition and their experiences of hospice services. It was explained to participants that while 12 diary entries were requested, preferably written once weekly, a minimum of eight entries over the diary period should be aspired to. No upper limit to the number of entries was set and participants were encouraged to write as many entries as possible. Some participants chose to continue writing their diary entries beyond the three months of their participation. Entries beyond the three month participation period were not subject to interpretative

phenomenological analysis but were used to validate the other diary entries alongside the interviews.

A choice of audio, paper or email diaries was offered to enable wider participation. An initial meeting was held during which participants were provided with a copy of the PIF and asked to complete a Demographic Information Form (Appendix J) and two Informed Consent Forms; one copy was retained by the participant and one by the researcher. They were also provided with a Diary Preface (Appendix K) and the relevant materials required for them to participate in the diary. A telephone conversation was set up for midway into the process and a meeting was established for the end of the 12 weeks for the interview and diary collection. As required by the NREC, a covering letter and Staff Information Form (Appendix L) was sent to their General Practitioner and copied to the participant. Weekly reminders were sent via email or text message, as per participants' preference, throughout their participation.

Diaries were guided using the Diary Preface (Appendix K). This was provided during the initial consent meeting and participants were invited to read through it and ask questions. The preface aimed to offer an example that might inspire thought but also enable free expression regarding the issues participants deemed relevant to share. All participant interviews were held at their most convenient venue; some were held at the local children's hospice site and others were at the participant's home. Participants were made aware that they could choose to stop the interview at any time. The interview topic guide (Appendix I) was provided and used as a prompt but participants were invited to speak freely about their experiences.

References:

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology*, 52(2), 250.

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Participant Information Form: Parental Experiences of Hospice in the Care of a Child through an Interpretive Phenomenological Analysis of Reflective Diaries.

You are being invited to take part in a research project designed to consider your experiences of being a parent to a child who has a condition that has led you to access a children's hospice service.

**What is the reason for the research?**

The reason this project is taking place is because it is understood that the views of the people who use hospice services are extremely important in helping hospices ensure they are offering the best possible care. Parents caring for children who are unwell have a good insight into the needs of the whole family and this makes their experiences rich with information that can be useful for hospices to find out what works and what doesn't. Hospices could use this information to support them in putting together a way of monitoring their support services and find out what they might be able to do differently. It is also helpful to have research to help others understand the experiences and difficulties parents face in the care of their children.

While there is no obligation for you to take part, as a parent with a family accessing hospice services, your experiences would be very valuable to this research. Thank you for taking the time to read this information.

**What will I be asked to do?**

The project will ask you to reflect on all your experiences of being a parent to a child who is unwell, it will also ask you to think about your experiences of receiving services from a children's hospice. In order to make sure that your whole experience has been captured in a way that allows you the freedom to disclose whatever you feel is important to reveal, you will be asked to make weekly entries in a diary. Alternatively, you could also arrange to take part in an interview with the researcher.

**How will the process work?**

If you decide to take part, you will be offered a choice of methods; you can complete a diary or take part in an interview lasting up to two hours. Diary entries can be written and sent by email to the researcher, or you can choose to have lockable paper diary or Dictaphone for an audio diary which will be collected from you at the end of the research, after twelve weeks. Entries can be as long as you would like them to be and you can make more than one entry each week if you would like to. Once your participation has ended, you will have the option as to whether your diary or a copy of your interview transcript is returned to you and the way in which it is returned.

**How do I know when and how to make a diary entry?**

As a parent to a child who is unwell, it is appreciated that you might be challenged by a busy schedule and have many things to worry about; understandably this may not make completing a diary a priority. Therefore, according to your preference, you will be sent a weekly text or email message to remind you to write your entry. After six weeks the researcher will call you to find out how the diary has been going and if there are any difficulties or problems you might want to talk about.

**If I want to take part, what do I need to do?**

If you decide you are interested in taking part you can either contact the researcher directly at the contact details below or you can complete a Consent to Contact Form and post it to her. The researcher will then contact you as per the method you have chosen and arrange a meeting to talk you through the project and ask for your informed consent. If you have chosen the diary method, the researcher will provide you with instructions on how to complete the diary. Once the meeting is over you can start the diary straight away and will start receiving your weekly reminders. After six weeks the researcher will phone you to find out how it is going, and at 12 weeks your final meeting will take place.

If you have chosen the interview method, the interview will take place after your informed consent has been taken.

### **What if I wanted to withdraw?**

You are able to withdraw yourself and/or your diary from the research at any point prior to submitting it. If this is the case then please contact the researcher who will be able to talk to you through this. If you decided to withdraw before the end of the 12 week diary process, but would like to submit some of your completed diary, it could be used if it had eight or more complete entries in it.

### **Will my information be confidential?**

The researcher will write a letter to your GP to let them know that you have consented to take part in the research. Aside from this, in most circumstances, your identifiable information will not be shared with the hospice or anyone other than the researcher. Your diary or interview transcript will be assigned a code to identify you by and your name and contact details will be stored separately. If your information is referred to in any publication of the research it will be presented anonymously and a disguise will be applied so that no one should be able to identify you. Diary entries will also be read on a secure computer at the University of Leicester. These precautions have been put in place to help you feel that you can say whatever you want to without worrying these things might be revealed to others.

The one exception to this rule would be if you were to communicate something that was considered to be very concerning such as risks to the safety of yourself or others. If this were to become a concern, the researcher would support you to access help from the most appropriate agencies, such as your GP or the Hospice, by telephoning and writing them a letter. This would only happen in concerning circumstances.

### **What is an Interpretive Phenomenological Analysis?**

Interpretative Phenomenological Analysis is a method that enables researchers to consider the similarities and differences across a number of diaries. These are then able to inform the researcher and help them understand the experience of accessing hospice services while caring for a child who is unwell.

### **What are the benefits for my family?**

It is hoped that the experience of taking part in this research would be a positive one in which you could express your thoughts and feelings. You will know that you have supported the researcher in her professional development and that you had helped hospices understand your family's needs so that they could continue to improve the care they offer to children and families.

### **Further information?**

If you would like any further information or to express an interest in taking part in the study then please do not hesitate to contact the researcher at:

**Contact:**

**Email:**

**Tel:**

### **Can I offer feedback or complain?**

If you would like to offer any feedback about your participation in the research or are unhappy about the conduct of the researcher, please address these in writing to the Course Director, NAME at:

ADDRESS OF UNIVERSITY

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Page 1 of 2

## The Parent Journey: Consent to Contact

**Study information sheet** I have received a Participant Information Sheet.

Please initial box

**Your permission**

I ..... (please insert full name)

agree to being contacted by the Chief Investigator of the project and am aware I will be under no obligation to take part.

**Your contact details**

Home tel. no.

Mobile tel. no.

Email address:

Address:

Post code:

**How to contact you**

Please select your preferred method of contact by placing a cross in the relevant box below.

Email

☐

Telephone

☐

Letter

☐

**Your signature**

Signature

Date

**To be returned to**

RESEARCHER'S  
CONTACT  
DETAILS

For Office Use Only:

Identifier

## Appendix H: Informed Consent Form, Version 3

Study Number:

Patient Identification Number:

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### INFORMED CONSENT FORM

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Title of Project: **Parental Experiences of Hospice in the Care of a Child through Reflective Diaries and Interviews.**

Name of researcher:

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 23.06.2013 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected. ☐
3. I understand that the data collected during the study may be looked at by individuals from the care team at HOSPICE NAME where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that my GP will be notified of my participation in this research project. ☐
5. I agree to receiving reminders about completing my diary (if applicable). ☐
6. I would like for my diary and/or interview transcript to be returned to me after the study has concluded. ☐
7. I understand that if anything I disclose raises concern about myself or others, it will be reported to the appropriate agencies. ☐
8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

Interview Topic Guide: Parental Experiences of Hospice in the Care of a Child through  
Reflective Diaries and Interviews.

**Themes/prompts:**

**1. *History and background***

- Of family - genogram/family tree
- Of child illness
- Of other children
- Family culture

**2. *Experience of being in a family with unwell child***

- Generally – immediate and extended family
- Vs other families who don't have a poorly child
  - o Issues that come up that may not come up for others
  - o Perceptions
- Having another child who isn't unwell?
- Having more than one child who is unwell?
- Daily functioning
- Jobs/career
- Financial impact (socioeconomic)

**3. *Support networks/services/other relationships (what helpful/unhelpful?)***

- Friendships
- Extended family
- Organisations (hospital, social care, hospice)
- Spiritual beliefs/understanding
- Professionals
- Siblings
- Group memberships

**4. *Learning***

- Schooling/education

**5. *Meaning of hospice***

- What services have been and currently received?
- Why accessed and why might not access, did not access earlier
- Why don't access any further services

**6. *Comparisons***



- To families without poorly child
- Between services accessed

**7. *What could be done differently?***

- In context of what has been accessed/provided in support

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Demographic Information Form: Parental Experiences of Hospice in the Care of a Child through an Interpretive Phenomenological Analysis of Reflective Diaries.

**Parental demographic information**

Title	
Forename	
Surname	
ID code	
Date of birth	
Address	
Postcode	
Preferred telephone no.	
Email	
Ethnicity	
Religion/faith	
GP name and address	

**Child demographic information**

Age	
Gender	
Hospice	
Approx length of contact with hospice	
Diagnosis	
Ethnicity	
Religion/faith	
GP name and address (if different from parent)	

**Other relevant information** (*I.e. family unit, school, stage of diagnosis*)

.....

.....

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NHS TRUST HEADER

Diary Preface: Parental Experiences of Hospice in the Care of a Child through an Interpretive Phenomenological Analysis of Reflective Diaries.

**Instructions for email diary**

*Step one:* Open your Microsoft Word document and type the date and your identifier at the top of the page then complete the entry. The entry should be at least a paragraph in length if you don't intend to write any other entries for the week.

*Step two:* Once the entry has been completed, save and password protect the document. See 'How to Password Protect a Word Document' for guidance on how to do this.

*Step three:* Open your email account and in the 'Subject' field type your ID number and the date of the entry.

*Step four:* Attach your corresponding diary entry and send the email to: EMAIL ADDRESS

**Instructions for paper diary**

*Step one:* In your lockable diary, use a clean sheet of paper and write the date on the top of the page.

*Step two:* Complete your entry. Your entry should be at least half a page in length if you do not intend to write any further entries for the week.

*Step three:* Once you have completed your entry, shut and lock the diary. You may choose to store it in a safe place for further confidentiality.

**Instructions for audio recorded diary**

*Step one:* For your first entry, the Dictaphone should be set at the beginning. Press the 'Record' button and begin by speaking in to the Dictaphone.

*Step two:* Once finished speaking into the Dictaphone, press the 'Stop' button. You may choose to store the Dictaphone in a safe place to ensure the confidentiality of your diary.

*Step three:* To make another entry, ensure the Dictaphone is set for after the previous recorded message, otherwise you might record over the previous diary entry.

**Points to note**

- The intention of the diary is to consider your experiences as a parent of a child with a life-limiting or life-threatening condition and your experiences of using hospice services.

- Diary entries should be recorded at least once weekly. Further entries are welcomed if you have more reflections you would like to share but one entry each week is important despite the number of entries you may have made the previous week.
- Please do not use surnames when writing your diary. This is in order to ensure the anonymity to others who may not have consented to taking part in this study.
- The presentation of your entries is not the focus of the diary; it doesn't matter if you don't get things like spelling or pronunciation perfect as long as it can be understood.
- You can choose to write or speak in whatever style or tense you would prefer, just try to make it clear who you are talking about. They will be anonymised so no one can recognise them once your diary is sent.
- Electronic diary entries will be bound and either these or your paper diaries will be returned to you once they have been analysed so that you have a record of your participation in the study.

### **An example entry:**

*“Our whole life as a family has changed, our expectations of parenthood, our dreams for the future. At times it can feel relentless; continuous care, fighting for support services, financial difficulties because our child’s needs require us to be available to care 24/7. Our other children do not get the attention they need; I know that it impacts on them. Today our community carer came from the hospice. This not only provides me with the practical support and an opportunity to take a break, but I enjoy their company. Having someone to talk to who really cares about us as a family and knows what it is like helps 😊.*

*Our other child attends sibling days and really enjoys going. She has a good relationship with the staff and has made friends with other children whose brothers or sisters access the hospice for care. Prior to attending the siblings days she didn’t understand why her brother was going to the hospice, at times she was worried about him and at other times she felt he got to do all the fun things. By involving her in the hospice she has a better understanding and I think she feels she gets some attention too.*

*I am really struggling to be at home all day with my little boy (age 1), he cries a lot and caring for him is so unpredictable 😊. Often I have to call an ambulance and this week we were blue lighted to hospital twice because of his seizures. I sit and watch him at home and am continually anxious that I will miss a seizure. I would like to play with him and be a normal parent. I have been attending the parent and toddler music and play group at the hospice. We get some great ideas of how to play and to position him in a way that enables play. Talking to other parents is helpful as they understand what it is like; at times we laugh and cry. However it is only once a month and at times like today when I know I should try and play with him and enjoy this time, I cannot motivate myself...”*

Thank you for participating. For any questions, queries or support in completing your diary, please contact NAME on:

**Email:**

**Tel:**

## Appendix L: Chronology of Research Process

Activity	Date Achieved
Feasibility assessment	March 2012 – April 2012
Research proposal submitted for consideration to university	April 2012 – May 2012
DClinPsy staff review of proposal	May 2012 – June 2012
Proposal amendments	June 2012 – July 2012
Peer review and protocol approval	July 2012 – August 2012
Service user reference group review	September 2012
Submission of protocol through IRAS	December 2012
NREC committee meeting, amendments and favourable opinion	January 2012 – February 2013
Sponsorship approval from NHS Trust	February 2013
Site-specific approvals	February 2013
Site access permissions and CRB	February 2013
Pilot participant recruitment and participation	April 2013 - August 2013
Substantial amendment 1	July 2013
Participant recruitment and informed consent meetings	April 2013 – September 2013
Diary process (3 months), interview meetings	April 2013 – December 2013
Interview meetings	July 2013-December 2013
Literature review	August 2013 – December 2013
Data transcription	August 2013 – January 2014
Interpretative Phenomenological Analysis and thesis write-up	January 2014 - April 2014
Thesis submission	April 2014



COMMITTEE ADDRESS

05 February 2013

Ms Lauren Sayers  
Clinical Psychologist in Training  
Leicestershire Partnership Trust  
University of Leicester, Department of Clinical Psychology,  
104 Regent Road  
Leicester  
LE1 7LT

Dear Ms Sayers

<b>Study title:</b>	<b>Parental Experiences of Hospice in the Care of a Child through an Interpretive Phenomenological Analysis of Reflective Diaries.</b>
<b>REC reference:</b>	<b>13/EM/0002</b>
<b>IRAS project ID:</b>	<b>120386</b>

Thank you for your letter of 02 February 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Non-NHS sites

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		04 December 2012
Evidence of insurance or indemnity		
Evidence of insurance or indemnity		23 November 2012
Investigator CV		15 November 2012
Letter from Sponsor		16 November 2012
Other: CV - Marilyn Christie		
Other: Non NHS SSI	120386/3907 24/7/370/184 749/260136	04 December 2012
Other: Diary Preface	1	15 November 2012
Other: How to password protect a word document	1	15 November 2012
Other: Demographic Information Form	1	15 November 2012
Other: Recruitment process mapping	1	15 November 2012

Other: Expression of interest from hospice organisation		22 November 2012
Other: GP Letter	1	02 February 2013
Other: Letter of Thanks	1	02 February 2013
Participant Consent Form: To Contact	1	15 November 2012
Participant Consent Form	3	02 February 2013
Participant Information Sheet: Staff	2	02 February 2013
Participant Information Sheet: Participant	2	02 February 2013
Protocol	1	15 November 2012
Protocol	2	02 February 2013
REC application	120386/3907 00/1/436	21 November 2012
Referees or other scientific critique report		24 October 2012
Referees or other scientific critique report		
Response to Request for Further Information		02 February 2012

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**13/EM/0002**

**Please quote this number on all correspondence**



We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

SIGNATURE OF CHAIR AND NAME

## Appendix N: Letter of Sponsorship from Research and Development Office



Lauren Sayers  
Clinical Psychologist in Training  
Leicestershire Partnership Trust  
University of Leicester  
Department of Clinical Psychology  
104 Regent Road, Leicester  
LE1 7LT

27<sup>th</sup> February 2013

Dear Lauren

**Re: Parental Experiences of Hospice in the Care of a Child through an Interpretive Phenomenological Analysis of Reflective Diaries**

**SPONSOR:**  
**NHS Trust**  
**FUNDER:**

**INDEMNITY: NHS Litigation Authority**  
**Trust Ref:**

Thank you for applying for NHS Permission to conduct the above study in the Trust. I am now in receipt of confirmation of a favourable ethical opinion (Ref 13/EM/0002 dated 5 February 2013), and have undertaken a full governance review (and have noted all subsequent amendments). This study has now been validated and reviewed according to the Standard Operating Procedure for research appraisal. NHS Trust has granted you full approval to conduct this research within the Trust on the condition that the Trust suffers no additional costs as a result of this study being undertaken. Your research has been entered onto the Trust's Research Database and is covered by NHS Indemnity. Study documents that have been approved are listed below (not exhaustive):

Document	Version	Date
Covering Letter		04 December 2012
Evidence of insurance or indemnity		
Evidence of insurance or indemnity		23 November 2012
Investigator CV		15 November 2012
Letter from Sponsor		16 November 2012
Other: CV - Marilyn Christie		
Other: Non NHS SSI	120383/3907 24/7/370/184 1/19/230136	04 December 2012
Other: Diary Preface	*	15 November 2012
Other: How to password protect a word document	*	15 November 2012
Other: Demographic Information Form	*	15 November 2012
Other: Recruitment process mapping	*	15 November 2012

Other: Expression of interest from hospice organisation		22 November 2012
Other: GP Letter	1	02 February 2013
Other: Letter of Thanks	1	02 February 2013
Participant Consent Form: To Contact	1	15 November 2012
Participant Consent Form	3	02 February 2013
Participant Information Sheet: Staff	2	02 February 2013
Participant Information Sheet: Participant	2	02 February 2013
Protocol	1	15 November 2012
Protocol	2	02 February 2013
REC application	120386/3907 00/1/436	21 November 2012
Referees or other scientific critique report		24 October 2012
Referees or other scientific critique report		
Response to Request for Further Information		02 February 2012

Please note that all research with an NHS element is subject to the Research Governance Framework for Health and Social Care 2005. If you are unfamiliar with the standards contained in this document, or the LPT policies that reinforce them, you can obtain advice from the R&D Office, or from

<http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopmentAZ/ResearchGovernance/fs/en>.

You must stay in touch with the R&D Office during the course of the research project, particularly if/ when:

- ☐ There is a change of PI;
- ☐ The project finishes (please complete a summary report form)
- ☐ Amendments are made, whether minor or substantial;
- ☐ Serious Adverse Events have occurred (must be reported within 24 hours of becoming aware of the event).

This is necessary to ensure that your indemnity cover is valid. Should any untoward events occur it is **essential** that you contact the R&D Office immediately. If patients or staff are involved in an incident, you should also contact the Clinical Risk Manager.

I hope the project goes well, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

Regards

SIGNATURE AND NAME OF R&D MANGER

19 March 2013

Ms Lauren Sayers  
Clinical Psychologist in Training  
Leicestershire Partnership Trust  
University of Leicestershire  
Department of Clinical Psychology  
104 Regent Road  
Leicester  
LE1 7LT

Dear Ms Sayers

**Re: Parental experiences of hospice in the care of a child thorough interpretive phenomenological analysis of reflective diaries.**

On behalf of  
Governance Committee has reviewed and approved  
research study at its meeting on 8 February 2013.

I am pleased to confirm that the Clinical  
participation in the above named

With best wishes

Yours sincerely

Chairperson  
Clinical Governance Committee and Trustee

## Appendix P: Letter of Favourable Opinion for Substantial Amendment 1

### NRES Committee

17 July 2013

Ms Lauren Sayers  
Clinical Psychologist in Training  
Leicestershire Partnership Trust  
University of Leicester, Department of Clinical Psychology,  
104 Regent Road  
Leicester  
LE1 7LT

Dear Ms Sayers

<b>Study title:</b>	<b>Parental Experiences of Hospice in the Care of a Child through an Interpretive Phenomenological Analysis of Reflective Diaries.</b>
<b>REC reference:</b>	<b>13/EM/0002</b>
<b>Amendment number:</b>	<b>Amendment 1</b>
<b>Amendment date:</b>	<b>23 June 2013</b>
<b>IRAS project ID:</b>	<b>120386</b>

The above amendment was by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	23 June 2013
Protocol	3	23 June 2013
Staff Information Sheet	3	23 June 2013
Participant Information Sheet	3	23 June 2013
Participant Consent Form	3	23 June 2013
Interview Schedules/Topic Guides	1	23 June 2013

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

#### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>13/EM/0002:</b>
--------------------

<b>Please quote this number on all correspondence</b>
---

Yours sincerely  
**Chair**

E-mail:

*Enclosures:                      List of names and professions of members who took part in the review*

*Copy to:*

## Appendix Q: Sample Page of Diary Transcript

	1	<b><u>Week 1</u></b>	<b>[mother-child narrative]</b>
	2	Dearest Darling Ollie,	Present in the 'here and now'. Assumes continuing existence
Anniversary of loss	3	Today marks 6 months since you flew from mummy's arms. I wonder what you would have	Death as flight-as if it was an intentional act of baby?
Loss of future with child/ loss of family	4	looked like at this stage? Would you be sitting up in your high chair like a big boy? Would	Envisioning development/ grieving the loss of this life stage.
	5	you still have Mumma's blue eyes or would Daddy now be able to claim those beautiful	Triangulating with 3 <sup>rd</sup> party (father). A shared loss.
	6	windows to your soul?	Preoccupation with continuing spiritual existence
	7		
Empathise/care for others	8	It has been such a strange couple of weeks. With all the visits to the hospital to visit Joe and	<b>[change to adult narrative]</b>
Expertise gained from grief experience	9	Bec. Looking into their eyes and seeing that very familiar fear and dread about losing one so	Peer support/altruism
	10	dear. Mummy feels like she has been able to help, especially when trying to explain to	EYES as windows to the soul
	11	Sarah what her mum is going through and all the different emotions that she so desperately	Altruism/expertise
Unpredictable course of emotion	12	wants to understand. But as we know only too well, this is not some 'step' programme where	Assistance/empathy
	13	you go through sequential stages. You experience different feelings and emotions but you	Criticism of received wisdom
Lack of control over own emotions	14	don't move on to the next stage, you just feel different. Then you may feel the same again at	Lack of control of emotions and events confirm her feeling of chaos
	15	a later date. It is a whirlpool! I recall the image/the diagram that Jenny from the hospice	Reference to hospice who have tried to conceptualise grief experience by providing expert knowledge to offer some way of structuring emotion.
	16	showed me about grief. I so long for the calm	

## Appendix R: Sample Page of Interview Transcript

Katie: And I think it's important because if you're just joining a [music group] where it's all just bereaved parents then I mean in a way being, not that I was forced, but being in a situation, you know, as I say I wasn't expecting to see a little baby in a, in a cot, and actually then seeing some of the other, especially the young children, the babies and their mummy's there with their suction tubes and their holding, and me, **visualising if Ollie was here** this would be me because his needs would have been great you know that would have been me carrying around my little oxygen pack and almost being sort of it was quite torturous really being, trying to imagine it but that is, **that process, that's going to happen at some time so for it to happen in that net, that bubble so to speak, is good because it, you have to challenge yourself**, you do, in order to drive through it and to and to survive because you you have an option, you can stay where you are and **that is not a very good place**, you know, or you know sort of **fight** or flight really. It's that situation. And I said to Ollie before he died that you know and when he died that **mummy will do something for you every day, you know you weren't blessed with a long life but for some reason mummy has been so it's, I do this for you because to this for yourself you don't really feel much about yourself, you feel, so to do it for him is different, that that drives you and maybe that's a parents love, a mothers love, or why there's this tough mummy syndrome going on at the hospice or the dad's as well, I don't want to discredit the dads at all in any of that, but erm, and I sort of said to him I will do something for you every day even if it is just to get out of bed, or to get dressed**, or to, you know, like I don't wear

**Meaning of integration within the music group theme**

Visualising 'what if' had her baby survived and how her life would have been having to care for him

Safety of being exposed through the music group. Through integration in the music group, the hospice support her to see reminders of her lost son that. She will have to face this outside of the hospice, in the real world.

**Fighting-the-fight theme**

**[mother-child narrative]**

Speaks to Ollie. Continuing bonds, holds him with her in her mind.  
**Attachment theme.**

Meeting own needs not a focus.  
**Unrelenting personal sacrifice**

Tough mummy syndrome. **Fighting theme**

Working against grief. Black represents grief and doesn't celebrate Ollie's life. **Fighting-the-fight theme**



## Appendix S: Epistemological Position

The epistemological position for the current research was one of contextual constructivism. This position acknowledges the influence of the participant's meaning, the researcher's interpretation and wider contextual factors in which the data was analysed (Madhill et al., 2000). In so doing, the interpretation of the participant and the researcher is most important and pursuing one established 'truth' is not a priority of the research; subjective meaning is an active part of the interpretation. The contextual constructivist stance also accepts that if a contextual variable during data collection was changed and data was collected at another time or another place, the unique account generated would be different (Madhill et al., 2000). In analysing the participant's perspective, quotes grounded within the diary and interview data have been extracted to demonstrate the themes identified by participants.

Such a position requires the reader to consider researcher characteristics and culture as these will influence the collection and interpretation of the data. The researcher was a white female in her late twenties who, while living elsewhere during data collection, had grown up in a similar geographical part of the United Kingdom, where the research had been carried out. As such, the hospice organisation through which participants were recruited was an organisation the researcher had had previous contact with through fundraising activity. While prior knowledge of working professionally with parents of children who had life-limiting conditions was minimal, during the design and implementation phases of the project, the researcher partook in a number of hospice activities to immerse herself in the culture of the organisation. In addition to this, participants required ongoing support to take part in the research consisting of at least weekly emails and telephone calls. The researcher also has a close friendship with a Family Support Team Manager working for the organisation. Her position as a researcher and Trainee Clinical Psychologist from an external organisation but

also as a regular attendee at group events may have influenced participant perspectives of her as a professional and also a group member. Due to the longitudinal nature of data collection, the relationship between participants and the researcher may have changed during the course of the research as familiarity increased.

## References:

- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20.

## Appendix T: Quality Issues

A number of concepts were considered during the course of the research in an attempt to achieve methodological rigour. Yardley (2000) suggests four areas a qualitative researcher should aim to address: they should be sensitive to the research's context; be committed to ensuring rigour; aim for transparency and coherence and; recognise the potential impact and importance of the research. This is corroborated by Morrow (2005) who emphasises the importance of reflexivity within the research and suggests 'trustworthiness' of qualitative research can be achieved in a number of ways.

In achieving some of these recommendations, the researcher strived to 'bracket'<sup>8</sup> through keeping a self-reflective journal recording responses and thoughts about events within the research process. The researcher also partook in an interpretative phenomenological analysis group with a number of colleagues from her university during which concepts emerging from the analysed transcript were explored reflectively. The researcher's two supervisors (research and clinical) considered individual sections of the analysed diary and interview transcripts to ensure issues raised by participants were considered from different positions. The researcher also: joined a number of groups relevant to the topic of interest through social networking sites; conducted a comprehensive review of the literature in the area; considered a number of children's hospice website pages sharing individual parent experience stories and joined their newsletter registers. The objective was to facilitate a grounding into the culture of the research, reducing personal bias by ensuring access to multiple perspectives within the area of children's hospice (Morrow, 2005).

---

<sup>8</sup> Bracketing is a process of monitoring the self. It can be achieved in a number of ways including holding conversations with experts in the field and keeping self-reflective journals.

References:

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology*, 52(2), 250.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-22

## Appendix U: Researcher's Declaration of Interest and Experience

The researcher had limited experience of the context of paediatric palliative care and children's hospice prior to initiating the research project. Some awareness of the organisation can be assumed resulting from a personal interest and through fundraising. The researcher developed a comprehensive awareness of the culture and ethos of the organisation during recruitment through participation in hospice activities. The design of the research required weekly contact with participants and this, combined with attendance at a music group and hospice events facilitated the formation of professional relationships with participants and staff. These experiences may have influenced interpretation of the transcripts. It was held in mind that a common cultural understanding can facilitate the development of empathy with participants, bridging the gap between researcher and participant (Madhill et al. 2000).

## References:

- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20.

## JOURNAL OF PALLIATIVE CARE / INFORMATION FOR AUTHORS AND CONTRIBUTORS

### CONTENT

The Journal of Palliative Care is international in scope and invites submission of English-language manuscripts from the various disciplines involved in hospice or palliative care. Reports of research projects and papers on studies designed to validate or evaluate currently prominent concepts and methods are welcomed. Original, interpretative articles that examine the foundations and advance the frontiers of hospice and palliative care are favoured.

#### Articles

- Reports of clinical and behavioural research
- Reports of studies to evaluate palliative care concepts and methods
- Interpretative papers, offering a philosophical, ethical, or legal -examination of goals, methods, trends, and issues of palliative care
- Historical surveys of trends and developments in palliative care
- Papers offering an original and intellectually exacting examination of broadly humanistic aspects of palliative care

MAXIMUM 5,000 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES.  
ABSTRACTS SHOULD BE KEPT TO A MAXIMUM OF 150 WORDS

#### Forum

Thought-provoking, tightly reasoned essays, expressing personal views on aspects of palliative care, suitably documented with reference to current literature.

MAXIMUM 1,000 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES

#### Hypotheses

New concepts requiring additional scientific investigation.

MAXIMUM 3,000 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES

#### Current Reviews

Detailed, critical and comprehensive surveys of concepts or experiences, particularly in palliative care, developed rapidly over several years.

MAXIMUM 4,000 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES



## Global Exchange

Reports and critical analyses, in editorial style, of hallmark events or developments in palliative care throughout the world.

MAXIMUM 1,600 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES

## Front Line Dispatch

A column that acknowledges that providers in an interdisciplinary field cannot always follow the in-depth evolution of significant trends in related areas of palliative care. Contributions are invited in a journalistic style that situate and synthesize current developments, issues, innovative clinical procedures, therapeutic methods, and promising novel methods of delivery.

RANGE 500–1,500 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES

## Orienteering

Editorial-style features that serve to indicate a main direction of thought about palliative care, somewhat as the compass and map offer guidance in the sport after which this section is titled. Papers featured in this section expand upon or synthesize several of the key ideas and information described in the current issue.

MAXIMUM 2,000 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES

## Case Report

The description and analysis of individual patient problems, clinical or psychosocial, and discussion of treatment solutions.

RANGE 500–1,500 WORDS, INCLUDING TABLES, FIGURES, CHARTS, AND REFERENCES

## Book Reviews

Essay-style reviews of books, journals, and papers offering a significant contribution to palliative care.

MAXIMUM 600 WORDS

## Letters to the Editor

Brief personal opinions on questions of palliative care under discussion in the journal. Permission to publish should be appended as a postscript. The Editor-in-Chief reserves the right to shorten such letters, to delete ad hominem attacks and similar comments, and to make other changes to accord with our style.

MAXIMUM 400 WORDS

## N.B. Note Well

Contributions are invited for a notice board of events and announcements. Space is limited.

## SUBMISSION OF MANUSCRIPTS AND CONTRIBUTIONS

All manuscripts of any kind whether solicited by or submitted to the Journal of Palliative Care are subject to review before a decision on publication is reached. A final decision on publication rests with the Editor-in-Chief. Manuscripts must not be under consideration by any other journal.

Send submissions to: Dr. David Roy, Editor-in-Chief, Journal of Palliative Care. E-mail (preferred method): [alison.ramsey@criugm.qc.ca](mailto:alison.ramsey@criugm.qc.ca). Mail: 4565 chemin Queen Mary, Montreal, Quebec H3W 1W5.

Submission: Electronic submission is preferred. Submit as a Word file, unless pdf format is required to view figures, etc. Also, please provide a copy of all figures, charts, illustrations, etc. in the software in which they were created.

Language: English.

Preparation: Manuscripts prepared in accord with the Uniform Requirements for Manuscripts submitted to Biomedical Journals ([www.icmje.org](http://www.icmje.org)) are acceptable. Manuscripts not biomedical in nature should be prepared in accord with the AMA Manual of Style ([www.amamanualofstyle.com](http://www.amamanualofstyle.com)). Additionally, the abstract maximum word count is 150 words.

References: References are numerical in order of appearance, not alphabetical. Journal references are as follows (please note punctuation, spacing, and capitalization):

- Jones JM, Cohen SR, Zimmerman C, et al. Quality of life and symptom burden in cancer patients admitted to an acute palliative care unit. *J Palliat Care* 2010; 26(3): 27-36.

Book references are as follows:

- Benson W. Long-term care in Indian country today: a snapshot. In: Kauffman J, editor. *American Indian and Alaska Native roundtable on long-term care: final report 2002*. Albuquerque (NM): Indian Health Service; 2002.

Please use Web references only as a last resort.

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