

**HOW DO CHILDREN'S NURSES WORKING IN HOSPICES  
MANAGE EMOTIONAL LABOUR AND PROFESSIONAL  
INTEGRITY IN LONG-TERM RELATIONSHIPS  
WITH PARENTS?**

**Thesis submitted in partial fulfilment of the degree of  
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## **SUMMARY**

This thesis is the result of an in-depth study which explored how six experienced children's nurses, working in hospices in England, managed long-term relationships with the parents of children in their care. The study took an inductive interpretive approach to narratives collected in audio diaries and further data elicited from follow-up telephone interviews.

Thematic analysis of individual participant accounts and the whole group are presented. For the whole group, three overarching themes were identified: Purposeful positioning, Balancing personability and professionalism, Coping with and counterbalancing emotional labour. The first two of these themes included a number of mindful and interrelated internal strategies used by the participants in order to manage the emotional and relational aspects of their role. The last theme represented sub-themes which were features of working at the hospice such as job satisfaction, positivity and fun and extraordinary peer support. These were identified as vital counterbalances to the emotional demands of the role.

Emotional intelligence (EI) theory was selected as a lens to explore the findings because many of the internal strategies were suggestive of EI traits. Moreover, it is also suggested that the hospice features outlined above require EI for engagement and may enhance EI; thereby better equipping the participants to cope with the emotional and relational demands of the role as well as acting as counterbalances.

Current EI models were not a perfect fit for the findings or indeed nursing generally, so a model spanning colleague relationships and nurse-parent relationships is presented in this thesis. Suggestions are made for the application of the findings and EI theory to recruitment and retention, formal nurse education, practice and staff development.

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#### **ABBREVIATIONS AND DEFINITION OF TERMS**

**CH** Children’s Hospice

**CPC** Children’s Palliative Care

**CPCET** Children’s Palliative Care Education and Training UK and Ireland  
Action Group

**CYP** Children and Young People

**DH** Department of Health

**EAPC** European Association for Palliative Care

**EoL** End of Life

**NHS** National Health Service

**NICE** National Institute of Health and Care Excellence

**NMC** Nursing and Midwifery Council

**RCN** Royal College of Nursing

**TfSL** Together for Short Lives

NB: In the data extracts, all names have been changed to protect confidentiality and anonymity. Ellipses have been used (...) to denote sections removed from the interview transcripts.

<b>DEFINITION OF TERMS</b>	
1. Children's nurse	Definitions are generally lengthy, so no one source has been used. An encompassing statement would be; a registered nurse who cares for children and young people from birth to mid or late teens. A fundamental concept is 'family-centred care', i.e. working in partnership with parents/carers and their involvement in care delivery, if desired.
2. Child	a young person aged up to their 19th birthday
3. Young person	a person from their 13th – 19th birthday
4. Parent	All natural parents, whether they are married or not. Any person who, although not a natural parent, has parental responsibility (as set out in the Children Act, 1989) for a child or young person Any person who, although not a natural parent, has care of a child or young person (having care of a child or young person means that the child lives with and is looked after by that person, irrespective of what their relationship is). (Education Act 1996)
5. Life-limiting /life-shortening conditions	There is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.
6. Life-threatening conditions	Those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.
7. Children's palliative care	The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach which includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and in children's homes. (World Health Organisation (WHO) 1998)*
8. Children's hospice services	Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services. Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose-built building.
2, 3, 5, 6 & 8 (Together for Short Lives (TfSL) 2016a), all others as referenced. *=seminal definitions	

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## CHAPTER ONE: INTRODUCTION

### 1.1. Overview of thesis

This chapter outlines the historical and contemporary context of children's palliative care (CPC) and children's hospice (CH) provision. A rationale for the study and its relevance are provided. Chapter 2 presents a literature review which focuses on the experiences of nurses working in CPC and the nurse-parent relationship. Chapter Three details the study design and methods and an evidence-based rationale for their selection. Chapters Four and Five present the results of data analysis on an individual and whole group basis with themes identified for both levels of critical exploration. Chapter Six explores the findings through the lens of Emotional Intelligence theory, including implications for CHs and CPC more widely. Chapter Six also outlines limitations, highlights my unique contribution and possibilities for future research. Finally, a dissemination plan is provided. Chapter Seven offers a brief conclusion and epilogue.

### 1.2. Contemporary children's palliative care

Death in childhood, once commonplace, is now rare. Infant and child mortality began to decline in the western world in the early 20<sup>th</sup> Century (Heywood 2001) as can be seen from the figures in Tables 1.1 and 1.2. When childhood death does occur it is accompanied by highly emotive responses (Lattanzi-Licht 1991; Morgan 2009) because contemporary society resists the notion that children die (Heller and Solomon 2005).

Table 1.1: Infant mortality rates in England and Wales 1912 - 2011				
Year	1912	1960	1981	2011
Infant mortality rates (up to age 1) *of live births	95 : 1,000 (ONS, 2013)	25.5 : 1,000 (Health Foundation, 2017)	11.1 : 1,000* (ONS 2013)	4.2 : 1,000* (ONS 2013)
			*A decrease of 62% over a 30 year period	
Data for 1912, 1981 and 2011 from ONS (2013). Data for 1960 from Health Foundation (2017)				

Table 1.2: Child mortality rates in England and Wales 1982 – 2012		
Year	1982	2012
Child mortality rates (age 1-14 years)	29 : 100,00*	11 : 100,000*
	*A decrease of 62% over a 30 year period	
Office of National Statistics (2014)		

Despite the historical provision of care for the dying and a wealth of contemporary adult palliative care literature, confusion remains about what this speciality involves (Payne et al. 2008). It is unsurprising then that there is an even greater lack of understanding of CPC, a speciality which is described as relatively ‘new’ (Carter et al. 2011). Its description as new is perplexing as children have always been cared for at end of life (EoL), sometimes in great numbers, as can be seen from the figures above. CPC has appeared in healthcare literature relatively recently (Liben 1996), prompted by the development of interventions to ‘palliate’ symptoms. So, it is palliation that is the contemporary concept rather than care of dying children. The ability to palliate then provides the opportunity to enhance the quality of the remaining lifespan, i.e. living life to the fullest whilst dying (Rallison et al. 2006; Konrad 2008; Rapoport et al. 2012). CPC is therefore an active approach and not just ‘*what you do when nothing else is left*’ (McNamara–Goodger and Cooke 2009, p. 46). In fact, CPC is defined by the World Health Organisation (WHO) (1998) as;

*The active total care of the child's body, mind and spirit, and also involves giving support to the family*

which

*begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*

CPC is delivered to those who have life-threatening and life-limiting conditions (Craft and Killen 2007). Life-threatening is defined as a condition where cure may be possible and life-limiting as a condition where there is no realistic hope of a cure (Together for Short Lives (TfSL) 2018a). Further clarity on categories of conditions cared for by CPC providers is given by TfSL (2018a), as shown in Table 1.3.

<b>Table 1.3: Categories of life-limiting and life-threatening conditions</b>			
Category	Key Characteristic	Description	Examples
1	Potential for cure - life is threatened, not necessarily limited	Conditions for which treatment may be feasible but can fail	Cancer
2	Period of normality despite having fatal diagnosis.	Conditions where premature death is inevitable but where there may be long periods of participation in normal activities	Some cardiac anomalies
3	Relentless deterioration from, or before, time of diagnosis.	Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extends over many years	Duchenne Muscular Dystrophy
4	Unpredictable course whose progression is not easily judged from natural history.	Irreversible but non-progressive conditions causing likelihood of premature death through complications	Severe cerebral palsy Traumatic brain injury Septic brain injury
Together for Short Lives (2018a)			

Children with diagnoses which fall into categories 2, 3 or 4 have an illness where no treatment is available, where life is limited and death is usually inevitable before the individual attains adulthood (Price and McFarlane 2009).

### **1.3. Policy context**

Children and young people are seen to have rights (UN General Assembly, 1989), as well as needs. The UN Convention is not a legal statute but is used to advocate for children (Glasper and Mitchell 2006). Throughout the U.K. the Children Act (1989) reinforces the UN Convention and legislates that the child's welfare is 'paramount' in all matters. However, CPC provision, like all health and care delivery, is influenced by political structures and statutes. The most recent palliative care bill is the Access to Palliative Care Bill 2015-16 (UK Parliament online 2018). This has progressed through the House of Lords but must continue through the Commons before Royal Assent is

sought. In common with previous Bills, e.g. Provision of Palliative Care Bill 2007, the focus is adults, leaving provision for children outside the mainstream. However, best practice guidance issued by the Department of Health (DH) (2008) aimed to improve outcomes and experiences for CYP who are living with life-limiting and life-threatening conditions and their families. More recently the National Institute of Health and Care Excellence (NICE) (2017) published quality standards for EoL care for infants, children and young people.

In devolved UK governments it appears that there is a greater recognition of the unique needs of children requiring palliative care. For instance, the Palliative Care (Scotland) Bill 2010 (Scottish Parliament online 2021) discussed CPC (although this Bill was later withdrawn and has not been resurrected). The Welsh Government (2013 & 2021) recognises children with life-limiting conditions as having distinctly different needs to adults which are broadly unmet (Welsh Institute of Health and Social Care 2015; Tŷ Hafan and Tŷ Gobaith 2020). In Northern Ireland the Department of Health (2016) outlines a strategy for children's palliative and EoL care but this is not enshrined in law. So, there is no national legislation underpinning CPC in the UK (Grinyer 2012).

The Together for Short Lives (TfSL) organisation was founded in 2011 following the merger of the Association for Children's Palliative Care (ACT) and Children's Hospices UK (TfSL 2011). It is now the largest UK CPC charity and is highly active in the political arena, constantly working to persuade the UK government to improve CPC provision (TfSL 2018b). Their influence, together with that of many UK experts, extends to the development of CPC services across the world. For example, the European Association for Palliative Care standards for CPC (EAPC 2007) cite many UK sources.

Due to its origins TfSL is an advocate for hospice-based care. Nevertheless, it recognises that the needs of children and families cannot be met solely by CHs and integration with hospital and other community-based services is imperative for effective service provision (TfSL 2013). However, much healthcare literature refers to CHs as a key provider of CPC for children with

life-limiting conditions (Brown 2007a; Taylor and Aldridge, 2017); in fact as the 'quintessential' provider (McNamara-Goodger and Feudtner 2012).

#### **1.4. Children's hospice care**

All care delivered by hospices comes under the umbrella of palliative care, but not all palliative care is hospice care (Lamers 2002). Palliative care is a broad philosophy of care whereas hospice care is an explicit model (Price and McFarlane 2009). The hospice appears to have been central to palliative care even before the modern movement was re-established by Dame Cicely Saunders in 1967, in fact dating back to the 11<sup>th</sup> Century (Hain et al. 2012). The first modern adult hospice was founded 15 years before the first children's facility.

The world's first CH, Helen House, was founded in 1982 by Sister Frances Dominica as a result of her friendship with the parents of Helen, who was permanently disabled by an inoperable brain tumour. The aim was to provide respite/short break care, friendship and support to families in a home-like environment (Worswick 1993). The CH model is different to that of adult hospices where care is usually delivered in the last six months of life or less (Strand et al. 2014).

The majority of children referred to hospices, and who benefit most from CHs provision, are those with significant, complex conditions many of which are neurological and/or degenerative (Gold 1997; Armstrong-Dailey and Zarbock 2001), i.e. Categories 3 and 4 of the TfSL (2018a) classifications. Caring for such children is physically and emotionally exhausting, so respite/short break care and family support are the main benefits for families (Swallow et al. 2011; Grinyer 2012; Champagne and Mongeau 2012; Lindley and Shaw 2014.). Indeed, families identify CHs as a lifeline without which they would struggle (Tÿ Hafan and Tÿ Gobaith 2020). However, despite the growth of the CH movement in the UK; 1 in 1982 to 54 in 2021 (TfSL 2021), provision is geographically 'patchy' (Brown and Warr 2007) as most are built by motivated individuals as a legacy for one particular child (Grinyer 2012). Furthermore, the role of the CH is poorly understood (Price and McFarlane 2009; Price et al. 2013; Munn, 2017), with perceptions of dismal places delivering EoL care to children with cancer (Craft and Killen 2007). However,



very few children with cancer are cared for in UK CHs (Vickers et al. 2007; Grinyer 2012). This is primarily because the child and family prefer to remain with a familiar oncology team and are often unaware of the services offered by CHs (Taylor et al. 2020). In addition, some healthcare professionals may not fully understand the role of CHs (Neeley 2009; Cooper 2017) due to it being a specialist area within the speciality of CPC. The relative dearth of literature on CH CPC further compounds this (McConnell and Porter 2017).

### **1.5. Rationale**

The majority of CH research focuses on clinical issues and outcomes for CYP. There is much less focus on other aspects of care which are more difficult to measure. Using Schon's (1988) analogies of hard ground versus swampy lowland, clinical CPC research is easily quantified and produces results which can easily be transferred into clinical outcomes, thus placing it on 'hard ground'. Research into non-clinical aspects of care reside in the 'swampy lowland' because results are often less quantifiable, the impact more difficult to evidence and overall, the topics studied matter less to wider society and possibly to nursing as a whole. Due to the focus of this study and its design, it would be classified as exploring what Schon (1988) refers to as the confusing messes of the swamp. Nevertheless, he highlights that such issues are often of the greatest human/practitioner concern and therefore worthy of investigation. The following section will provide a rationale for this study of the emotional and relational aspects of the nurse-parent relationship in CHs.

It is estimated that in the UK there are more than 49,000 CYP aged 0 to 19 with life-limiting or life-threatening conditions (TfSL 2018c). Children with such conditions are living longer (Nageswaran et al. 2018), so relationships between hospice staff and families can span decades (DH 2008). Much of the care provided by CHs is respite/short break care (Grinyer 2012), so these are intermittent, long-term care relationships and emotional labour is high (Maunder, 2013), leaving health professionals vulnerable to burnout (Larson, 2006). Coupled with the common features of a CH (Box 1.1) this makes the experience of working in a CH significantly different from other clinical areas, particularly the nurse-parent relationship. Certainly Maunder (2013) identified

that nurses working in CHs found the homely, informal atmosphere helpful when relating to families and coping with their own emotions.

<b>Box 1.1: Common features of a Children's Hospice</b>
<ul style="list-style-type: none"> <li>➤ Small cohesive units</li> <li>➤ Close staff groups</li> <li>➤ Informal, homely atmosphere</li> <li>➤ 1:1 staff patient ratio</li> <li>➤ Often no uniform</li> <li>➤ No rigid hierarchy</li> </ul>
(Woolley 1989; Worswick 2000; Barnes 2001; Sheldon and Speck 2002; Hoban 2003, Maunder 2006 & 2013).

The role of the children's nurse includes family centred care which is seen as a partnership between the nurse and family members. This is a continuum which will fluctuate depending on the needs of the child and family (Smith and Coleman 2009). Working as a children's nurse in a hospice takes this partnership a step further to 'care of', i.e. the definition of care delivered in this environment is:

*a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual.*

(TfSL 2016a, p1)

Therefore, the care of the family is as much a part of CH work as the care of the child. However, although this holistic care of the whole family is ideal and appealing there is little preparation or guidance for children's nurses on how to manage the long-term relationships with children and families which often occur in CHs (and other CPC settings). The EAPC (2013) advocated a more relationship-centred approach to the education of the CPC workforce and this particularly relates to reciprocal influences between those who give and receive care. In the case of CPC this promotes an understanding of the subjective world of the child and their family who live with the threat of death and the uncertain trajectory of many life-limiting conditions (EAPC 2013).

Although relationships between nurses and children/families in CPC have been researched (Erikson 2008; Maunder 2013; Erikson and Davies 2017), none of these studies have been carried out exclusively in CHs.

Subsequently the influence of this unique care environment on nurse/parent relationships has not been explored specifically, leaving a gap in the literature. The importance of understanding workplace culture in palliative care has been highlighted by Kelly (2019) as a means of creating working environments which are beneficial for both staff and patients.

### **1.6. Relevance**

Although specialised, it is hoped that findings from this study could also be applied to other areas where vulnerable patients and families are cared for over long periods of time. Furthermore, the CH movement continues to grow, so challenges to working in this environment are important considerations for staff and employers (Taylor and Aldridge 2017). As highlighted earlier there is an expectation that CH nurses will provide care to families as well as children and although there are published competencies (EAPC 2013; RCN 2018) for CPC delivery, there is nothing which relates specifically to CHs. Consequently, there is no substantial guidance on how to provide the emotional, social and spiritual care families need, and CH organisations expect, whilst operating within the confines of professional boundaries and without exceeding one's own capacity for emotional labour. Therefore, any research which can contribute to an understanding of how nurses currently working in this field manage emotional labour and professional integrity in their long-term relationships with parents would be useful.

The next chapter will provide a critical review of research and associated literature which explores nurses' experiences of working in CPC and the nurse-parent relationship.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1. Introduction**

The approach used in this literature review was a scoping review using a systematic process rather than a systematic review. The rationale being that the breadth and different perspectives required would not lend itself to such a narrow approach. However, many of the tools and approaches used are drawn from systematic review literature. It is important to note that traditionally, scoping reviews map or chart the key findings of the literature (Arksey and O'Malley 2005) but in this case the literature will also be analysed as described in Section 2.4.

### **2.2. Search strategy**

Optimal search strategies are important, particularly for qualitative studies (Wilczynski et al. 2007), as the methodologies used are diverse and relevant articles are distributed across a wide range of journals (Brunton et al. 2012). As recommended by Pearson et al. (2007) a subject librarian was consulted to ensure an optimal search strategy. During this appointment subject headings, key words and how to search effectively were discussed, particularly the use of Boolean operators such as 'AND', 'OR' and 'NOT' together with the identification of words used in other countries/ cultures. The importance of replicating the search in each database was also highlighted. Table 2.1 was devised following advice from the librarian and used to search the CINAHL, PsycINFO, ASSIA, Scopus, Medline and British Nursing Index databases.

<b>Table 2.1: Subject headings and key words used in literature search</b>			
Child	Palliative care	Family	Nurse
(MH "Child+")	Terminal care (subject heading)	Parents+ (subject heading)	Nurs*
Child*	Palliative care (subject heading)	Caregiver	Healthcare provider*
Paediatric*	Terminally ill patients (subject heading)	Care N1 giver	Healthcare professional*
Pediatric*	Hospice	carer	"Health care provider**"
Adolescen*	Eol	Father	"Health care professional**"
Youth*	End N5 life	Mother	Nurses+ (subject heading)
Teen*	Terminal* N2 care	Mum*	Nursing staff+ (subject heading)
Young* N3 people	Dying N2 child*	Dad*	healthcare worker*
Young* N3 person	Terminal* N2 ill*	Guardian	"health care worker**"
Kid	"Life limit*" (illness / condition?)	Legal guardianship+ (subject heading)	Nursing care+ (subject heading)
Juvenile*	"Life threatening"	Professional family relations (subject heading)	
Boy*	Hospice and palliative nursing (subject heading)	Parent*	
Girl*	Critical illness (subject heading)	Parental attitudes (subject heading)	
(MH "Minors (Legal)")	LTI		
Baby			
Babies			
Infant*			

### 2.3. Study selection criteria and procedures

Dundar and Fleeman (2014) outline a five-step approach for managing study selection (Table 2.2), which was used for this search.

<b>Table 2.2: Process for managing literature</b>	
Step 1	De-duplicate references and pilot use of inclusion criteria
Step 2	Screen all titles and abstracts identified via searches using inclusion criteria (Stage 1)
Step 3	Obtain full-text papers of all potentially eligible articles
Step 4	Apply inclusion criteria and select full-text papers for inclusion in review (Stage 2)
Step 5	Report results of your searches (Using PRISMA diagram -See Figure 2.1)
(Dundar and Fleeman 2014, p 48)	

Using EndNote made the de-duplication process straightforward.

Nevertheless, differences in how databases store material necessitated manual identification. Reference lists of all sources were scanned to identify any additional relevant items. EndNote was used to store sources as recommended by Booth et al. (2015). Microsoft Excel was used to create a document with multiple tabulations to record all sources and their progression or discontinuation at each stage of the selection process. This was useful for checking whether items identified via back chaining had already been identified and dismissed at an earlier stage. Although entering all the articles from the initial scan of titles through to the final selection was time-consuming, I found Excel more agile than EndNote for managing and sorting the sources.

Because the world's first CH opened in 1982 and CPC is a relatively new speciality, the search criteria was set to encompass articles published from 1982 until the time of the search (January 2018). EBSCO alerts were set up from then onwards. Due to a dearth of research specifically relating to CHs most hits related to CPC in hospital settings. However, this literature did provide an insight into the views of nurses in relation to parent-nurse relationships in CPC settings. To maximise transferability, articles primarily relating to CYP oncology were taken forward to the review rather than those covering CPC in intensive care, neonatal and other acute settings. The rationale being that the relationships with parents in oncology would be built over a significant period due to the duration of treatment regimens (Klassen et al. 2012) and, therefore, likely to be more closely applicable to the long-term relationships explored within this study. Some studies collected data from across all CPC settings so the relevant elements of these were

included. Articles reporting research into relationships between nurses and parents of children with complex chronic illness were also included as, although this is not necessarily labelled as CPC, the nature of the healthcare offered, prognosis and length of nurse-parent relationships mirrors elements of CPC in oncology, community, and hospice settings. Furthermore, childhood life-limiting illness has only recently been segregated from chronic illness to become a separate research focus (Ware and Raval 2007), so limiting the search solely to life-limiting conditions in children would be constrictive. Indeed, many children who have complex needs and are dependent on technology are cared for in CHs (Rallison et al. 2006) and many nurses working in CPC would use the term complex needs interchangeably with life-limiting, and life-threatening (Nicholl 2007; Whiting 2014 a & b).

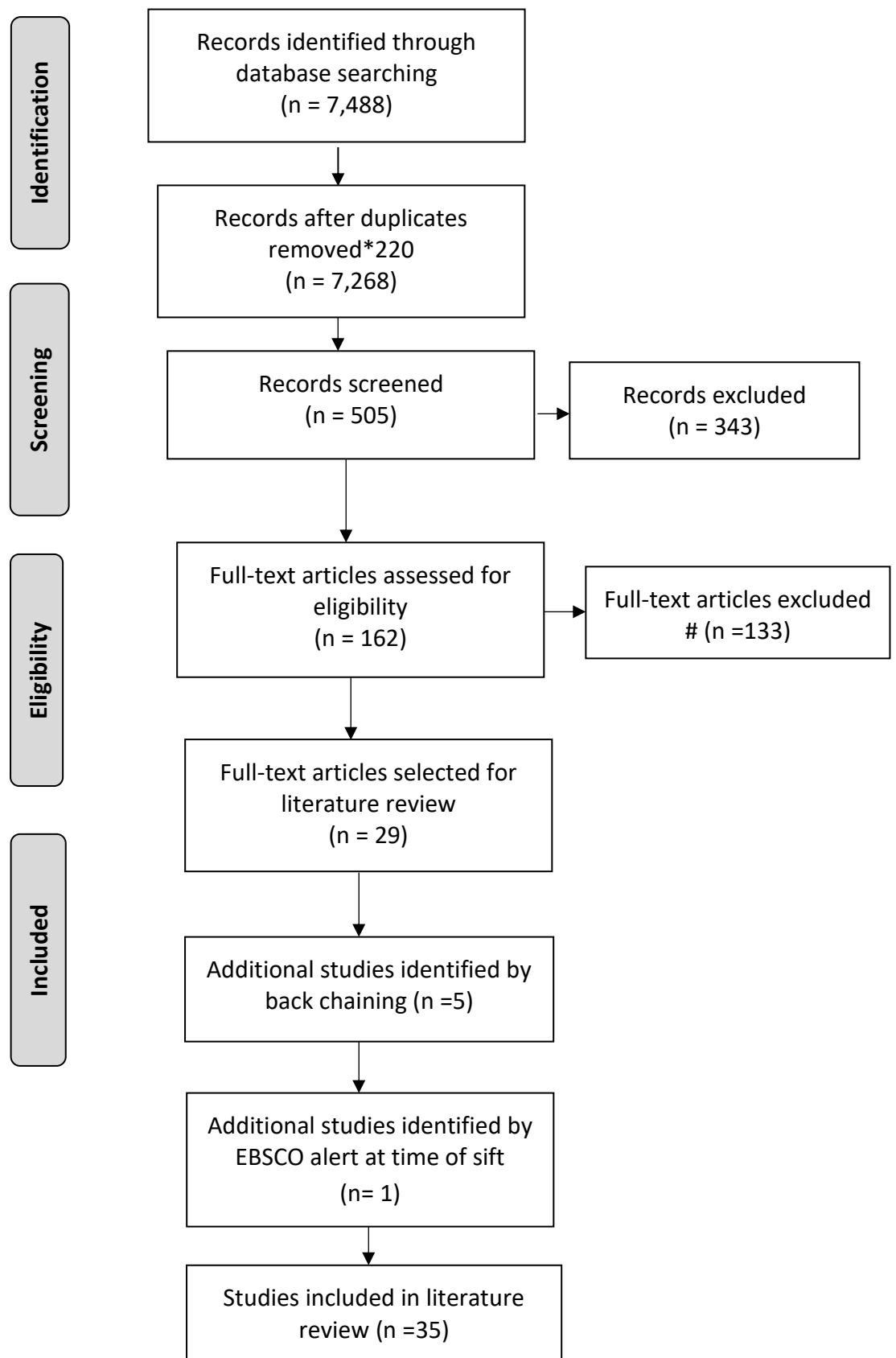
The initial search produced the following hits: CINAHL 982, PsycINFO 443, ASSIA 1,568, Scopus 1,385, Medline 1,493 and BNI 1,617; a total of 7488. Elimination of 220 duplicates reduced this to 7,268. 6,763 of these were deemed unsuitable following a review of titles, leaving 505 abstracts for screening. A further 343 records were rejected at this stage. These comprised 36 which were non-English language publications, 144 which were deemed suitable for background information only and/ or were not empirical research and finally 163 which were focused on practice in areas which did not feature situations, circumstances or environments that were relevant to the study. This left 162 items to be retrieved and the full article screened for eligibility. 133 articles were excluded at this stage (noted as # in Figure 2.1 and detailed in Table 2.3.), leaving 29 for inclusion in the review. Back chaining identified five additional studies and one relevant EBSCO alert was received before the final sift. Leaving 35 relevant articles to take forward to the review.

<b>Table 2.3: Reasons for exclusion of full text articles</b>	
Reason	Number
End of Life Focus	25
Not research	22
Short parent/ nurse relationship	22
Post bereavement data collection or bereavement focus	17
Literature review	16
Insufficient data on nurse/parent relationship	10
Not CPC	8
Service evaluation	5
Focus on education	2
Adult focus	4
Focus on social work	2
Total	133

The PRISMA Flowchart (Figure 2.1) maps the process of identification through to inclusion.



**Figure 2.1: PRISMA Flowchart (Adapted from Moher et al. 2009)**



Inclusion of grey literature, including strategic documents, can give a broader perspective (Hopewell et al, 2007). The subject of this review particularly lent itself to this approach as views of emotive topics may be more fully revealed through less formal avenues. Godin, et al. (2015) stated that searching for grey literature in a systematic manner is difficult and requires specific search methods, i.e. grey literature databases, customised Google searches, targeting specific websites and consulting subject experts. Based on this approach the search for unpublished and grey literature included the sources in Box 2.1 which produced 7 relevant items, giving a total of 42 items for the review.

<b>Box 2.1: Unpublished and grey literature search</b>	
British Library	Together for Short Lives website
Conference Proceedings	E-Hospice website
Institute for Health & Social Care Research (IHSCR)	Hospice UK website
NIH Re-PORT	Local children's hospice website
New York Academy of Medicine Grey Literature Report	European Association for Palliative Care website
Open Grey	The Worldwide Hospice Palliative Care Alliance website
ProQuest	Google
International Children's Palliative Care Network Website	

## 2.4. Appraising the literature

As the literature being reviewed is primarily qualitative, an adapted version of the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al. 2007) checklist was the main tool used to assess the quality of reporting in each research article selected for the literature review. This tool was chosen based on reviewing one article using both the COREQ checklist and Critical Appraisal Skills Programme (CASP) Qualitative Research appraisal tool (CASP 2018) then comparing the elements extracted by each tool. Although COREQ was favorable, the prompts under each sub heading of the CASP tool were also helpful, so a combination of both was used. In

addition, COREQ was designed for studies which use interviews and focus groups, so the addition of elements of the CASP tool ensured that all types of methods could be explored. Indeed, it is recognised by Rolfe (2006) that, due to the wide range of approaches used for qualitative research, it is not possible to develop one tool which can be applied to all. In the case of mixed method studies or purely quantitative work a CASP tool appropriate to the study design was used.

## **2.5. Structure of the review**

The review is divided into three sections:

2.6. Nursing in children's palliative care

2.7. Nurse-parent relationships in children's palliative care

2.8 Literature Review Conclusion

## **2.6. Nursing in children's palliative care**

### **2.6.1. Introduction**

This section of the review aims to assemble an understanding of nurse perspectives of working in CPC. Rushton and Ballard (2011) highlight the juxtaposition in experience of working in CPC. On one hand the complexity of this practice area (Lehna 1999; Clarke and Quin, 2007) offers immense job satisfaction (Woolley et al. 1989; Korzeniewska-Eksterowicz 2010; Klassen et al. 2012; Rodriguez and King 2014) and personal growth (Beaune et al. 2018). Conversely it can result in high levels of practitioner stress, distress, emotional labour, compassion fatigue and burnout (Maytum et al. 2004; Brown 2007b; Rushton and Ballard 2011; Pearson 2013). This part of the review will therefore be divided into negative and positive aspects of working in CPC. Each section will be divided into sub-themes which have arisen from analysing the literature. These are:

Negative aspects of working in children's palliative care

- Stress, distress, coping and emotional labour
- Burnout and compassion fatigue

## Positive aspects of working in children's palliative care

- Job and compassion satisfaction
- Personal or post-traumatic growth

## **2.6.2. Negative aspects of working in children's palliative care**

### **2.6.2.a. Stress, distress, coping and emotion labour**

Occupational stress, which impacts on home and work life, has been identified as an issue for nurses working across a range of CPC settings (McCloskey and Taggart 2010). Data collected by McCloskey and Taggart (2010) via semi-structured focus groups with CH nurses, community children's nursing (CCN) teams and hospital-based nurse specialists, indicated that whilst some stressors were common to all areas of practice, others were unique to specific roles and intermittent according to workload pressures.

Conversely, in their hospice-based study Woolley et al. (1989) found that three quarters of staff working in a CH were under comparatively little stress. Nonetheless 25% were under a great deal of stress, particularly those who had experienced a recent personal bereavement and had unresolved grief about a death prior to them starting work at the hospice. More recently Maunder (2013) and Kase et al. (2018) discovered broadly similar issues in their samples of CPC workers (community, hospice and hospital based). Indeed, emotive personal experiences are often a motivator for seeking work in a hospice, perceived as 'giving something back' (Hill-Jones 2008; Katz 2016). Therefore, this pre-existing potential for stress should be something which managers are alert to.

In addition to personal, pre-existing grief Woolley et al. (1989) found that another source of stress was the sense of impotence that staff felt when they were unable to ameliorate distress or meet a family's needs. Witnessing the diminishing quality of life for children with neurodegenerative disorders and physical deterioration alongside intact intellectual faculties, in conditions such as Muscular Dystrophy, was particularly distressing. Children with cancer were also a source of anguish as the participants knew that there was a high possibility that a member of their own family would contract a similar

condition. An expected death which did not occur was also found to be stressful and this mirrors the impact this has on parents (Fowler-Kerry 2008). Participants in the Woolley et al. (1989) study found any difficulties in their relationships with families stressful, a finding supported by others (McCloskey and Taggart 2010; Koreniewska-Eksterowicz et al. 2010; Klassen et al. 2012). Likewise those who did not articulate or show their feelings were seen as a challenge and this left staff feeling uncertain of how they could help (Woolley et al. 1989). Woolley et al. (1989) suggest that the many difficulties outlined by their participants may escalate in situations where respite, day care, symptom control or EoL is carried out in the family's own home. This idea was supported by McCloskey and Taggart (2010) who found that CCNs in their sample highlighted these difficulties, which further escalated when the CCN lived and worked in the same community.

General work/life balance difficulties leading to conflicts at home have been identified by some authors (Woolley et al. 1989; McCloskey and Taggart 2010). For example, behaviours such as excessive periods worked after the end of a shift (Kushnir et al. 1997; Erikson and Davies 2017) and communication with colleagues or families when not on call. This may be linked to the findings of Maytum et al. (2004), McCloskey and Taggart (2010) and Rodriguez and King (2014) who identified that professionals involved in caring for children with life-limiting conditions were often stressed because they felt pressurised to deliver more than the agreed care package, sometimes stepping outside of their role. This was often due to gaps in provision, because the child's condition was so rare or the illness trajectory so uncertain, resulting in staff feeling that they had to compensate for this in some way.

Home life and family relationships were also impacted in other ways such as sleep disturbance, irritability and difficulty in 'switching off' (McCloskey and Taggart 2010). However, those who had a very clear sense of where their job ended and the personal realm began felt that this protected them from the likelihood of stress and burnout (Kushnir et al. 1997; Maytum et al. 2004). In Woolley et al.'s (1989) CH study some staff struggled with perspective on ordinary life events, seeing these as trivial compared to what they witnessed at work. Findings from hospice studies are, of course, influenced by the

certainty that the child will die, whereas those working in oncology care for many CYP who will be cured.

As well as being stressful, working with children with life-limiting conditions can be distressing. Not only do practitioners witness and deal with the anguish of parents and children, they also have to deal with their own feelings (Woolley et al. 1989 and 1991; Lattanzi-Licht 1991; Rushton and Ballard 2011; Buder and Fringer 2016). The nature of relationships between nurses and families is explored more fully in Section 2.7 but is mentioned here because while close nurse-family relationships are a source of satisfaction, the emotional entanglements nurses have with families can be burdensome (Maunder 2006; Clarke and Quin 2007; McCloskey and Taggart 2010; Rushton and Ballard 2011; Pearson 2013; Maunder 2013; Rodriguez and King; 2014; Doe and Katz 2016). Parents are aware of the emotional toll that CPC nursing takes on professionals (Nahra 2008; Dolan 2013).

Klassen (2012) and Pearson (2013) noted that although experience in the field of CPC led to refinement of clinical, communication and interpersonal skills, the emotional distress felt by healthcare professionals continued to be high no matter how long they had worked in the speciality. Emotional strength is appreciated by parents (Woolley et al. 1991) but Rushton and Ballard (2011) and Cargill (2014) highlight that healthcare professionals should not be expected to compromise their own wellbeing. However, with experience, many staff can identify triggers and develop coping strategies to counteract emotional demands and avoid feelings of helplessness (Woolley et al. 1989; Maytum et al. 2004; Rushton and Ballard 2011). Maytum et al. (2004) found that coping strategies could be personal or work related, short or long term. Examples of personal coping strategies identified by Woolley et al. (1989) and Maytum et al. (2004) were exercise, meditation, keeping a journal, focusing on non-work relationships, having fun, thinking positively and a sense of humour. Long-term personal strategies included developing a personal philosophy (also recognised by Rushton and Ballard 2011 and Beaune et al. 2018), faith, spirituality and self-analysis. Other strategies were achieving a work/life balance, developing supportive personal relationships and formal support such as counselling.

In common with Kushnir et al. (1997), Maytum et al. (2004) found that successful short term, work related, coping strategies were keeping strictly to one's own job role, debriefing at work and declining additional shifts. A common long-term work-related strategy was developing supportive and honest professional relationships. This was later supported by Lehna (1999) and more recently by Buder and Fringer (2016) and Beaune et al. (2018), who found that developing meaningful relationships with colleagues in work, particularly when staff had worked through highly emotional and difficult times together, nurtured peer support which acted as 'buffer' against stress, compassion fatigue and burnout. Nevertheless, McCloskey and Taggart (2010) found an individual's capacity for coping could both increase and diminish with experience, usually dependent on the number of deaths experienced within a specific duration and/or emotional overload due to the complexity of care or relationships.

Cargill (2014) and Beaune et al. (2018) described the distress experienced by practitioners who work with life-limited children as vicarious traumatisation. Beaune et al. (2018) highlights the need to regulate one's own feelings by remaining composed, articulating and sharing personal sadness and/or developing compassion. They refer to this as emotional growth which has elements of emotional labour as outlined by Hochschild (1983). Both Pearson (2013) and Cargill (2014) identified high levels of emotional labour in CYP oncology nurses. Likewise Maunder (2006) discusses emotion labour in CPC and, in her PhD study, explored the emotional management of children's nurses caring for CYP with life-limiting conditions and their families (Maunder 2013). She found that CPC nurses in CHs and the community adopted informal professional personas to make families feel more comfortable. However, this increased their own levels of emotional labour as did the need to establish long-term relationships with children and families.

#### **2.6.2.b. Burnout and Compassion fatigue**

Burnout and compassion fatigue are closely related (Kase et al. 2018).

Burnout is defined as occupational distress due to uncontrollable workplace

factors, manifesting itself in dissatisfaction and a feeling of being overworked (Kavalieratos et al. 2017). Compassion fatigue is secondary traumatic stress experienced by providers through repeated exposure to the suffering of their patients, which may result in a reduction in empathetic abilities and an inability to enter into a caring, compassionate relationship (Figley 1999; Rushton and Ballard 2011; Cargill 2014). Due to the stress and emotional challenges of working with children with life-limiting and life-threatening conditions and their families CPC practitioners are at risk of burnout (Clarke and Quin, 2007; McCloskey and Taggart 2010; Klassen et al. 2012; Cargill 2014). However, others such as Koreniewska-Eksterowicz et al. (2010) Davies et al. (2017) and Beaune et al. (2018) suggest that high levels of job satisfaction and connectedness with families' decreases the risk of burnout.

Maytum et al. (2004) used a qualitative descriptive approach to explore compassion fatigue and burnout in nurses working with children with chronic conditions and their families in inpatient tertiary care, ambulatory care, community health home care and CH. Although the nurse participants worked in a range of settings the findings across them were similar and are supported by the more recent McCloskey and Taggart (2010) study. A broad range of physical and emotional symptoms of compassion fatigue and burnout were reported and many nurses were able to recognise their own early indicators for this. Symptoms of compassion fatigue and burnout were found to be similar although the severity of symptoms was worse with burnout. Several participants described a continuum from compassion fatigue to burnout rather than two entirely separate things, although burnout was usually precipitated by a cycle of repeated compassion fatigue. Compassion fatigue was seen as transient, but burnout was longer lasting and generally led to the inability to function at work or home. Participants described over 30 triggers, primarily work related but in a quarter of cases these related to the nurses' personal life, which is similar to the findings of Woolley et al. (1989), Koreniewska-Eksterowicz et al. (2010) and Kase et al. (2018). Maytum et al. (2004) found that work related triggers were: caring for children with chronic conditions and their families, professional roles, work overload and broader system issues. Care specific triggers were painful procedures and excessive sadness often linked to the length of the



relationship and the high likelihood of death. Half the participants identified that repeatedly listening to the families' stories and dealing with their emotional burdens was a trigger for compassion fatigue and burnout, as was parental expectation and dependence. Aspects of these findings were more recently supported by Kase et al.'s (2018) cross sectional pilot study of compassion fatigue, burnout and compassion satisfaction, carried out across the U.S. They used an adapted version of the validated Compassion Fatigue and Satisfaction Self-Test of Helpers (Figley 1999; Stamm 2002) and a professional and personal characteristics questionnaire to collect data from CPC nurses and doctors. As just 18% of respondents appeared to be suffering from compassion fatigue and 12% from burnout, the researchers concluded that concerns about burnout and compassion fatigue in the CPC healthcare practitioner population may be unfounded. It could be suggested that, for some, the positive aspects of working in this field help to counteract the negatives. Alternatively, those experiencing compassion fatigue and burnout may not have participated in the research.

### **2.6.3. Positive aspects of working in children's palliative care**

#### **2.6.3.a. Job and compassion satisfaction**

Although CPC may be distressing, healthcare providers find it rewarding because they gain immense satisfaction from the impact they have on children and families (Liben et al. 2008). Kase et al. (2018) suggest that job satisfaction and positive professional experiences have been linked to higher compassion satisfaction. Compassion satisfaction is defined as emotional fulfilment derived from caring for patients (Stamm 2002). As health professionals working in CPC generally report high levels of job satisfaction (Korzeniewska-Eksterowicz et al. 2010; Beaune et al. 2018) they may experience high compassion satisfaction, despite the challenges of their role. Both factors are likely to be positive for staff and service users, particularly as job satisfaction in CPC appears to be an indicator for effectiveness and quality of care (Maunder 2006; Morgan, 2009).

In the Woolley et al. (1989) CH study, job satisfaction was measured using a rating scale and factors contributing to the level of job satisfaction were explored via a semi-structured interview. Job satisfaction was high, even in those who were identified as being stressed. Half of the study participants were registered nurses, so the findings are likely to be representative of nurses' experiences and views. The authors state that a limitation of the study is its small sample. This may be true in comparison with the numbers usually expected in a quantitative study. Nevertheless, at that time (in terms of the numbers of CH in existence) this was one of the only samples of its kind. A particular source of job satisfaction in this environment was having time to spend with children and families and being able to deliver highly personalised, bespoke care, a finding supported by Maunder (2013). In the participants' view this was a unique feature of the CH (Woolley et al. 1989; Maunder 2013). All participants in the Woolley et al. (1989) study valued the homelike, informal environment of the hospice and the lack of a rigid hierarchy and 'red tape'. Likewise, both studies identified that the cohesive staff group and informal mutual peer support was the most important protective factor for coping with their work and led to high levels of job satisfaction. This finding is important considering the lack of peer and management support identified in CPC areas other than CH (Maytum et al. 2004; McCloskey and Taggart 2010). Woolley et al. (1989) concluded that specific factors relating to the environment and organisational structure of the CH may ameliorate some of the negative factors reported in studies undertaken in other primarily cure focused environments.

Another study carried out exclusively in the CH environment was undertaken by Korzeniewska-Eksterowicz et al. (2010). Theirs was a small-scale quantitative study of job satisfaction in health professionals working at a Polish CH. Job satisfaction was found to be good overall despite the high emotional burden. The highest levels of satisfaction were found in healthcare professional's relationships with children and their families, particularly the strength of the relationship and the communication between the two parties. In common with Woolley et al. (1989) relationships with peers were a source of support and increased job satisfaction. However, unlike Woolley et al.

(1989), who found that the lack of rigid hierarchy at Helen House added to job satisfaction, Korzeniewska-Eksterowicz et al. (2010) found that communication and relationships between healthcare workers and the 'management' were poor and therefore less harmonious, despite an even smaller total staff group than in the Woolley et al. (1989) study. Like Woolley et al. (1989), Korzeniewska-Eksterowicz et al. (2010) found that the ability to deliver high quality care was cited as being a source of high levels of job satisfaction. In their case, high quality care was thought to be facilitated by particular attention to recruitment, preparation, induction, probation, prior qualifications and experience, together with a commitment to ongoing specialist education. Although written much more recently than the Woolley et al. (1989) article, the Korzeniewska-Eksterowicz et al. (2010) report is written at a similar point post founding of the hospice (6 years after opening). In the same way that Woolley et al. (1989) concluded that high levels of job satisfaction ameliorate stress, Korzeniewska-Eksterowicz et al. (2010) suggest that job satisfaction decreases emotional overload and thus the chance of burnout.

Klassen (2012) found that witnessing personal growth in parents was a source of satisfaction for healthcare professionals. Although participants in Klassen (2012) and Rodriguez and King (2014) recognised the personal emotional impact of being in a situation where they could not fundamentally change the devastation felt by the family, they enjoyed being part of the experience, working alongside families and gained satisfaction from the small differences they could make. The extent of satisfaction felt by CPC nurses is clear in the proliferation of video blogs found online. Examples of which are:

*It's so rewarding, the care that you are able to give them is so unique ... We are very, very privileged to work here* (Tŷ Hafan, 2018a)  
and

*Working in children's palliative care is the best thing I've done in my life.*  
(TfSL 2016c)

Alleviating a parent's distress in some way and contributing to memory making activities such as hand/footprints or moulds were reported as particularly rewarding (Klassen 2012; Rodriguez and King 2014). Being

appreciated and valued by families was a positive aspect of participants' work, particularly when parents took the time to articulate this via cards, phone calls or emails (Klassen 2012). Although nurses made up a significant proportion of the total participants in this study (27%), they were not the largest group (Doctors = 39%), so the findings may not be wholly applicable to nursing.

Like Woolley et al. (1989), Kase et al. (2018) explored the polar ends of practitioner experience in CPC. They carried out a cross sectional quantitative pilot study of compassion fatigue, burnout and compassion satisfaction. SPSS was used to analyse the data which showed that 25% of participants experienced compassion satisfaction, compared to 18% with compassion fatigue and 12% with burnout. Compassion satisfaction was thought to be primarily due to participants not currently experiencing any distress due to coping and self-care activities. Kase et al. (2018) suggest that self-care activities facilitate the development of resilience, subsequently contributing to high levels of compassion satisfaction, despite the challenges of working in CPC. Since the study is quantitative it measures prevalence rather than lived experience, but it is useful in indicating that for this population the notion of compassion satisfaction was the dominant one. Furthermore, although this study was published almost 30 years after Woolley et al. (1989) the findings are broadly similar from the perspective that more staff experienced satisfaction from their role in CPC than those who experienced stress. Additionally, even those who were stressed still experienced positives from their role (Kase et al. 2018).

#### **2.6.3.b. Personal or post-traumatic growth**

Tedeschi and Calhoun (2004) define post-traumatic growth as the experience of positive change which occurs following highly challenging events. It results in changes to personal priorities and interpersonal relationships, an increased sense of personal fortitude, and a richer existential and spiritual life. Personal growth is a concept which has been identified in parents of children with life-limiting conditions. Likewise suffering and witnessing suffering can be transformative for healthcare practitioners (Rushton and Ballard 2011). Beaune et al. (2018) recognised that positive effects of

working with children with life-limiting conditions and their families, such as personal growth, are under-researched and suggest that exploration of this concept has potential to increase job satisfaction and wellbeing of practitioners. Data collected for a study into coping in Canadian health professionals working with children with life-limiting conditions (Muskat et al. 2014) were subjected to secondary analysis by Beaune et al. (2018), who used the constructs of post-traumatic growth provided by Tedeschi and Calhoun (2004) to analyse interview scripts from 25 practitioners who each had more than 10 years' experience. The sample comprised almost equal numbers of social workers, nurses and physicians. Like Vishnevsky et al. (2015), who studied personal growth in adult oncology nursing, Beaune et al.'s (2018) analysis revealed clear evidence of personal growth across all participants. Beaune et al. (2018) identified three constructs of personal growth; new or altered life perspectives, enhancement of personal resources and benevolence. The theme of new or altered life perspectives included a gratitude for one's own life and blessings, an appreciation of others strength and resilience and redefined priorities (similar to Lattanzi-Licht 1991). In addition, participants were often humbled by the strength and resilience of others and this changed the way that they viewed their own lives. Enhanced personal resources came about by learning from children and families which helped to develop practitioners own personal strengths alongside humility and recognition of their limitations (also discussed by Lattanzi-Licht 1991) and learning lessons about clinical practice, i.e. learning from the expert parent, also reported by Rodriguez and King (2014). Many felt that doing this work had made them 'a better person', thus indicating a sense of satisfaction. Beaune et al.'s (2018) participants talked of the importance of doing their work well as they were conscious of potential long-term effects on the family's grief if they did not (Konrad 2008). A feeling of contributing something of value and significance was labelled as benevolence. Feeling satisfied and proud of their work seemed to help to manage the emotional toll and was linked to professional self-esteem and high levels of job satisfaction.

#### **2.6.4. Summary**

Working in CPC can be stressful, distressing and involves emotional labour (Maytum et al. 2004; McCloskey and Taggart 2010; Maunder 2013; Pearson, 2013). However, positives such as job and compassion satisfaction alongside personal growth may go some way to counteracting or even outweighing the negatives (Woolley et al. 1989; Koreniewska-Eksterowicz et al. 2010; Beaune et al. 2018; Kase et al. 2018). Instances of staff stress burnt out or compassion fatigue may be due to non-work-related factors, organisational factors, intermittent 'spikes' in workload pressures and specific incidents relating to a child or family (McCloskey and Taggart 2010).

### **2.7. Nurse – parent relationships in children's palliative care**

#### **2.7.1. Introduction**

The discussion in Section 2.6.2 mentioned that whilst close nurse–parent relationships in CPC enhance job satisfaction they also carry an emotional burden, hence managing them is a challenge (Rushton and Ballard 2011; Erikson and Davies 2017). Of particular note are the tensions between closeness and professionalism (Woolley et al. 1989 & 1991; Doe and Katz 2016; Buder and Fringer 2016; Erikson and Davies 2017). The nature and extent of these relationships is more fully explored here via empirical and grey literature. The discussion is divided into themes identified from the literature which encompass both parental and professional perspectives. These are:

- Bonds, attachments and trust
- Sharing the journey
- Going the extra mile
- Boundaries and integrity

#### **2.7.2. Bonds, attachments and trust**

McCloskey and Taggart (2010) and Pearson (2013) identified that longstanding relationships increased the intensity of mutual attachment between nurses and families, making CPC a unique type of nursing.

'Connectedness' between healthcare professionals, particularly nurses and families in CPC was highlighted by Clarke and Quin (2007) Erikson and Davies (2017), Davies et al. (2017) and Beaune (2018).

Doe and Katz (2016) used a case study approach to explore emotional entanglements with a client or patient within which practitioners provided care based on their own emotional needs rather than those of the child and family, termed as countertransference. This has been identified as an issue in CPC which increases stress (Maytum et al. 2004). Doe and Katz (2016) found that when asked about emotional attachments, experienced professionals strongly refuted this. Nevertheless case studies revealed evidence of strong emotional involvement with children and families, particularly when the nurse identified closely with them. Interestingly the first named author used the pseudonym 'Jane Doe' because she felt she would be labelled as unprofessional for admitting her emotional involvement. The fear of being seen as unprofessional for becoming emotionally involved with children and families seems evident in the emphasis placed on professionalism in a video blog promoting the work of CH nurses, i.e.

*We are professional nurses, the care that we give is professional but you can't help but take them to your heart. (Tŷ Hafan 2018a)*

The actions of nurses can have a profoundly positive affect on parents, as demonstrated in the personal accounts by Nahra (2008) and Dolan (2013). In Nahra's (2008) account the nurses' attachment and love for the child was deemed to be as important as clinical competence. Further, having a 'good day' was dependent on a nurse with whom they had a strong bond being on duty (Nahra 2008). Similarly this quotation, from a father's social media post, gives his perception of the relationship between his family and CH nurses.

*It's not just about a professional duty but a desire to give as much of themselves as is humanly possible ... alongside compassion, support, understanding and most of all love. (Tŷ Hafan 2018b)*

Neal's (2015) exploration of media representations of CPC also found that 'love' for children in the nurses' care was prevalent parental perspectives. For example:

*all the nurses love (child's name) and she loves them.*

(Neal 2015 page 17)

Likewise Konrad's (2008) phenomenological study found that mothers often used the word 'love' to describe how they perceived the professional caregiver felt about their child. The word 'love' is commonly used in everyday language but when used to describe positive feelings about a child it usually relates to something deep, long lasting and unconditional. It is doubtful that this is, in fact, what nurses were feeling. Furthermore, this is not the role of the professional nurse (Buder and Fringer 2016).

Commonalities between nurses and particular children or parents, such as similar background, life experiences, or ages of their children have been found to intensify connections on the part of the family (Woolley et al. 1991) and the nurse (Doe and Katz 2016; Erikson and Davies 2017). Furthermore, mutual respect and nurses' recognition of parental instinct and expertise, strengthened trust and reciprocal bonds (Woolley et al. 1991, Lattanzi-Licht 1991; Steele 2002; Konrad 2008; Whiting 2014b; Rodriguez and King 2014; Beaune et al. 2018). Mutuality and reciprocity are also seen as a way of achieving partnership and a balance within the inherent power inequity in the parent/professional relationship (Konrad 2008; Davies et al. 2017).

Physical contact, i.e. social touch and embracing between those who have an emotional bond or attachment is commonplace (Suvilehto et al. 2015). Such physical contact has been found to be beneficial for patients and families in palliative care (McPherson and White 2015). Such social physical contact can be calming, reassuring, provide comfort without using words and help someone cope with illness and related stressors (Routasalo 1999). Personal reflections by children's nurses such as Fletcher (1999) detail how the 'use of self' in this way occurs when comforting parents in CPC. Pearson's (2013) UK wide phenomenological study of paediatric oncology nurses identified that the length and depth of the relationship between nurses and families influenced whether nurses would use physical contact as a means of comfort. Further, Maunder's (2013) study of children's nurses delivering hospice and community palliative care found that they were engaged in warm interactions and close personal contact such as hugging



both colleagues and children and parents. Appreciation of this is demonstrated by parental accounts such as Nahra (2008) who recalled being regularly physically comforted by nurses during her emotional outbursts. However, McPherson and White (2015) acknowledged that this level of emotional closeness, interpersonal intimacy and engagement may be unfamiliar and uncomfortable for some in respect of professional boundaries. Moreover, Maunder (2013) found that CH nurses who did not hug their peers, children and families were seen as transgressing the expected 'norm' and this caused disquiet within the team.

Trust is also an important factor in relationships between parents and CPC healthcare professionals (Contro et al. 2002). For example Steele (2002) and Klassen et al (2012) identified that trustworthiness was fundamental to nurses being seen as 'part of the family'; in that healthcare professionals working with life-limited and life-threatened children recognised the trust parents placed in them and felt privileged to be welcomed into their lives. Clarke and Quin (2007), Konrad (2008), Korzeniewska-Eksterowicz et al. (2010) and Buder and Fringer (2016) discuss the role of good communication, honesty and authenticity in both building relationships in CPC and as pre-requisites for trust. Konrad (2009), Rodriguez and King (2014), Davies et al. (2017) and Mooney-Doyle et al. (2017) identified parental trust in healthcare professionals extended to reliable advice or even trust to make a decision on their behalf if they were overwhelmed and felt unable to do so. Konrad (2008) particularly highlighted the need for parents to trust health professionals to be sensitive and skilled enough to know when to lead and when to be led by parents.

Although long-lasting relationships, bonds and attachments between nurses and families are primarily positive, there are negatives. For example, both Fletcher (1999) and Pearson (2013) identified that in the case of children with cancer, families did not uptake hospice care even though they may be encouraged to do so by hospital staff. This was because the relationships built over time with hospital staff were more important to the parents and child than the 1:1 specialised, bespoke care they would receive at the hospice where the environment and staff would be unfamiliar. This was a

source of both satisfaction and frustration for staff. Other less positive aspects of long-lasting relationships occurred when these were underdeveloped due to communication difficulties (McCloskey and Taggart 2010; Klassen 2012) and this became a barrier to effective care (Davies et al. 2008). Wider family issues, anger or aggression and dissatisfaction with services frequently lead nurse-parent relationship difficulties which often escalated over time (McCloskey and Taggart 2010; Klassen 2012).

### **2.7.3. Sharing the journey**

Woolley et al. (1991), Rodriguez and King (2014) and Davies et al. (2017) found that parents greatly appreciated healthcare professionals who would take the time to just be with them, not necessarily undertaking clinical duties, just getting to know them. O'Shea and Kanarek (2013) offer a case study written from the personal parental perspective of Kanarek, a nurse as well as an affected parent. The major issues identified were the importance of working in partnership with families, really listening to them; effective, open, sensitive communication across all aspects of care; helping families to maintain hope, not necessarily for a cure but for comfort and for good things to happen to their child and the family. These themes, for an adapted type of hope and helping families navigate their journey as parental caregivers, are supported by Smith et al. (2018). The art of being present with families, staying close and keeping the child and the family at the centre, is the underlying theme which runs through the work of Rushton (2005), O'Shea and Kanarek (2013) and Smith et al. (2018). Similarly Mooney-Doyle et al.'s (2017) study found that a major parental expectation of the healthcare professional was to empower them to carry on with their everyday lives and maintain family relationships.

As well as featuring in empirical studies, journeying alongside families and a sense of shared history is a prevalent theme in grey literature such as video blogs. For example:

*making a real difference for families and accompanying them on their journey ... and that for me is where the reward is (TfSL 2016c)*

Being part of the family is a common theme across the literature. For example Steele (2002) identified that becoming 'just like part of the family' was a result of being seen as trustworthy and thereby permitted to accompany the family on their journey. A recruitment campaign encouraging children's nurses to consider hospice nursing also highlights this notion.

*I want to be part of their family when they need somebody*  
(TfSL 2016c)

Other media sources such as Johnson (2016) also highlight being part of the family, as does this social media post by a father describing CH care;

*... strangers when you arrive, who become family by the time you leave.*  
(Tŷ Hafan 2018b)

This is an aspect of the nurse-parent/child relationship that needs careful management in terms of the journey belonging to the family and not the healthcare professional (Davies et al. 2017), however much they may empathise (Papadatou 1991). Davies et al. (2017) undertook a 3 year prospective grounded theory study which explored parental and healthcare professional perspectives of best practice in CPC provider/parent interaction. A major finding was that the healthcare professionals who demonstrated best practice empathised rather than sympathised with parents. They defined empathising with parents as a shared experience, in which they entered the parents' story to try to understand their perspective. These 'best practice' practitioners felt that differentiating their own experiences and feelings from that of the family was integral to empathy; described as the ability to become a 'fellow traveller' without being overwhelmed by their own feelings.

#### **2.7.4. Going the extra mile**

As discussed in Section 2.6.2, healthcare staff, particularly nurses, often felt obliged to work beyond the remit of their role in relation to hours worked, tasks and contact with colleagues/families after the end of their shift (Kushnir et al. 1997; Erikson and Davies 2017). Despite the personal cost of stress, work/life imbalance, home conflict, burnout and compassion fatigue, these additional duties were found to be undertaken with a sense of conscience and willingness to help families who were facing the early death of their child

and for whom service provision was often lacking (Rodriguez and King 2014). Both staff and parents felt that these actions strengthened their relationship (McCloskey and Taggart 2010; Pearson 2013; Rodriguez and King 2014; Davies et al. 2017). However, once these bonds were developed, nurses often felt that they needed to take on even greater responsibility for the family, so these additional activities became the 'norm' (McCloskey and Taggart 2010; Pearson 2013; Rodriguez and King 2014). Undertaking these additional duties sometimes fulfilled the nurses need to be needed (Cargill 2014) and gave rise to feelings of indispensability (Lattanzi-Licht 1991). This perpetuated the behaviour but eventually led to long-term effects such as compassion fatigue and burnout (Maytum et al. 2004). Further, if this meets the nurse's need, rather than that of the child or family, it is outside the bounds of the therapeutic relationship (Roberts et al. 2015). Further, professionals need to beware of taking over when the family may just need a little support, i.e. becoming the 'omnipotent rescuer' (Benner and Wrubel 1989); a theme which echoes Lattanzi-Licht's (1991) piece, drawn from professional experience and her personal reflections as a bereaved mother.

Several studies identified that additional duties were also expected by parents. This was usually couched in terms of availability and flexibility (Woolley et al. 1991; Steele 2002; Rodriguez and King 2014; Whiting 2014b) or a greater level of commitment (Dolan 2013), but in essence meant that parents wanted healthcare staff to be available whenever they were needed. This was recognised by parents as 'going the extra mile' and staff who did so were highly valued (Konrad 2008; Nahra 2008; Rodriguez and King 2014). Witnessing the huge difference these actions made to families and the appreciation shown by parents further perpetuated staff self-expectation to exceed their designated duties. McCloskey and Taggart (2010) found that this often led to a very intense relationship between one nurse and a family, particularly for hospice nurses and CCNs. Such intense relationships increase stress and it is unlikely that any one person can fulfil all the needs of a child and family (Woolley et al. 1991; Rodriguez and King 2014).

### **2.7.5. Boundaries and integrity**

Maintaining the balance between over-involvement and distancing oneself from clients, as a protective measure, is an issue in nursing generally (Griffith 2013) and has been identified in nurses working in a range of CYP areas (Totka 1996; Roberts et al. 2015). Since involvement, caring and interpersonal connections form the basis of nursing, Benner and Wrubel (1989) identify that the path between over-involvement and distancing oneself is a narrow one which often requires experience to navigate. Nevertheless Cargill's (2014) qualitative exploratory study involving six experienced CYP oncology nurses identified that even for this knowledgeable and skilled population there was an increased risk of violating professional boundaries, due to the length of involvement and the emotive nature of their role.

Maintenance of professional boundaries is essential in upholding the reputation of the nursing profession (NMC, 2018). Definitions of professional boundaries vary but most include reference to a line or an edge which should not be crossed. Most authors agree that the focus of nursing relationships must be on care and treatment (Griffith, 2013) and what is therapeutic for the child and family (Roberts et al. 2015). Some term this as the 'zone of helpfulness' existing between the extremes of over and under involvement (NCSBN, 2018). The importance of finding the right level of professional involvement in CPC was underlined by Maguire and Price (2007). They described this as 'connected', which they defined as compassion, conscience and commitment alongside the professionalism required by the NMC Code (2018). This is a significant challenge for children's nurses working in this field (Erikson and Davies, 2017) and one which has been termed as an occupational hazard (Cargill, 2014).

Woolley et al. (1991), Kushnir et al. (1997), Maytum et al. (2004), Rodriguez and King (2014) highlight that facilitating the parental expectations of flexibility, availability and emotional strength over long periods of time can result in healthcare professionals becoming overinvolved and overstepping boundaries. However, from Nahra's (2008) personal perspective, rather than

interfering with the nurses' professionalism this higher level of commitment enhanced it.

Further Dolan's (2013) personal account of her children's ten-year healthcare journey used phrases such as 'the nurses became part of our family', 'girlfriends of mine', 'surrogate aunts, advisors and confidants'. She also recounted attending nurses' weddings. Dolan (2013) described her experience as truly holistic care and clearly what occurred was highly beneficial to her and her family. However, it does raise the question of where work ends and personal life begins. Indeed, when responding to Stein et al (1989), Moncrieff (1990), wishing to convey that hospital CPC offers a service comparable with CHs, revealed actions which would be seen to be outside the professional role, e.g. staff babysitting in the family home in their free time.

This is further complicated by the informality desired by parents (Steele 2002; Davies et al. 2017) and encouraged by some philosophies or environments of care (Woolley et al. 1989 and 1991; Martinson 1995). Woolley et al (1991) identified that a sense of humour and sharing a joke with children and families was an important means of forming a relationship within the CH setting. More recently Maunder (2013) found that the homelike environment of the CH and home visiting led children's nurses working in these CPC environments to assume informal, non-traditional professional personas to make families feel more comfortable. Indeed, Maunder (2013) found that an informal approach was encouraged in the hospice as there was an expectation that nurses would socialise with families and each other during their daily work and at mealtimes.

Informality does pose risks for the care relationship to be misunderstood by families, e.g. they may perceive the relationship to be a friendship with all the closeness and personal exchanges this brings. Similarly healthcare professionals may unwittingly become drawn into conversations and situations which sit outside the therapeutic relationship outlined by Roberts et al. (2015). This was evident in the study by Erikson and Davies (2017) which identified that some nurses perceived some 'extra mile' activities and contact

with parents outside work as a violation of professional boundaries, whilst others felt that this was an extension of their role and a valuable source of support. Even those who clearly identified some of their behaviours as boundary violations felt that this could not be helped due to their attachment to the family. Participants in this study who successfully managed professional boundaries adopted behaviours which 'buffered' them from the emotions surrounding their work, such as keeping a distance and strict separation of personal and work life. This included careful limitation of personal disclosure and always keeping the focus on the child and family.

The enhancement of bonds due to commonalities between nurses and particular children or parents, identified earlier, (Woolley et al. 1991; Erikson and Davies, 2017) can also pose a risk for losing perspective, erosion of a clear sense of one's role and transgression of professional boundaries (Lattanzi-Licht 1991). Healthcare professionals can easily identify commonalities with parents as they have access to much of their personal information. However, personal disclosure on the part of the healthcare professional needs to occur for the parent to identify a commonality. Self-disclosure is a recognised part of initiating, developing, maintaining and terminating therapeutic relationships (Ashmore and Banks 2002) and is appreciated by parents of life-limited and life-threatened children (Steele 2002; Davies et al. 2017). However this reciprocity requires careful management and skill to discern what is appropriate and inappropriate (Lussier and Richard 2007).

The reflection by Maguire and Price (2007), in which the correct level of involvement in CPC alongside professionalism is highlighted, brings one to the concept of professional integrity. In essence this means engaging with the values of your profession by being both 'self-regarding and other-regarding' (Petterson 2008). Rushton and Ballard (2011) Brown (2007b) and Pearson (2013) found that the uniqueness of each family and their situation meant that nurses continually reconstructed their approach to achieve holistic, bespoke care whilst attending to their own emotional labour and integrity. Similarly Erikson and Davies (2017) found that maintenance of integrity is achieved when nurses integrate two competing but essential

aspects of the nursing role, i.e. behaving professionally and connecting personally. When nurses were skilful at this they were able to provide high-quality care within a clearly defined therapeutic relationship. The process was highly individualised to each nurse and each family. Unsuccessful mitigation of tensions led to compromised integrity, characterised by boundary breaches, compassion fatigue and burnout. Further, a nurse's professional registration may be at risk if a boundary breach is deemed worthy of sanctions by the NMC.

Professional boundaries are complex and, as shown from the literature discussed here, particularly relevant to CPC nursing. Seeing them as straightforward, 'black and white' or a defined line is unrealistic (Erikson and Davies, 2017). Both Cargill (2014) and Buder and Fringer (2016) stressed that understanding and managing professional boundaries is something which cannot really be taught but is learnt from role models, experience and a sense of one's own vulnerabilities and resilience. Erikson and Davies (2017) suggested that further research is required in other CPC areas, such as hospices, since professional boundaries are particularly challenging in this field of nursing work.

#### **2.7.6. Summary**

This section of the review has brought together two parties involved in CPC: parents and healthcare workers. The major themes identified by analysis of the literature were bonds, attachment and trust, sharing the journey, going the extra mile, boundaries and integrity. My overarching impression of this literature is that the very things which enhance the nurse-parent/family relationship are those which raise healthcare professional self-expectations. Ultimately this can lead to challenges which may be difficult for the nurse to manage. The concept of integrity as discussed by Erikson and Davies (2017) in terms of how nurses manage these relationships is of particular note. It demonstrated how boundaries which in theory may be defined lines, but in practice are not, can be configured on a case by case, nurse by nurse basis. Successfully integrating, rather than balancing the concepts of connecting personally and behaving professionally, outlined by Erikson and Davies (2017) promotes quality care, quality relationships and professionalism. For



me this conjures an image of a jigsaw with pieces that can be configured in many ways to achieve a form which is of a defined size but has a variety of shapes.

## **2.8. Literature Review Conclusion**

Literature exploring nurses' experiences of working in CPC was examined, revealing both negative and positive aspects. It appears that a 'Catch 22' exists in terms of the very things that are positive about the role also have negative effects but subsequently ameliorate them. Nurse-parent relationships were explored and similarly the positives of close, long lasting relationships and accompanying families on their healthcare journey were factors which posed emotional challenges. Moreover, self-imposed expectations presented difficulties in managing boundaries and integrity. Grey literature was also included to give a more in-depth personal perspective which remains unrevealed when adhering to traditional literature search methods.

Studies which focus specifically on relationships in CPC are a fairly recent addition to the literature underpinning this field of healthcare, perhaps due to the relative 'newness' of the speciality (Liben 1996) and professional curiosity about the tension of professional closeness and distance within this field, which is ever-growing due to developments in medical science (Downing 2012; TfSL 2018c). This merits further exploration. Indeed, following publication of an abridged version of the nurse-parent relationships section of this review (Brimble et al. 2019 – Appendix 1) I was contacted by two cited authors. Both highlighted that the issue of managing professional boundaries with families in children's nursing is an under-researched and ongoing issue. They thanked me for keeping the conversation going. This was encouraging and reaffirmed my belief that this was an area worth exploration, particularly in the hospice setting as contemporary studies undertaken exclusively in this environment are rare. In addition to being valuable to practice, gaining a greater understanding of how professional integrity and emotional labour are successfully managed by children's nurses working in CPC, the findings could also positively influence pre and post registration nurse education.

### **2.8.a. Revisiting the literature**

Ongoing database alerts were set up in January 2018 when finalising the original search. Between February 2018 and March 2021, there were numerous alerts but very few were relevant to my study. For absolute certainty I duplicated the search in March 2021. No studies, other than those identified in alerts, were located. There were two new pieces of literature (Konukbay et al. 2019; Dunbar and Carter 2021). These mirrored some of the themes identified in the original review: job satisfaction, empathy, compassion fatigue and close nurse-parent/child relationships. So these pieces did not offer any significant new perspectives. They did, however, confirm that the researched experience of nurses working in CPC had remained static throughout the course of the thesis.

## **CHAPTER THREE: RESEARCH DESIGN AND METHODS**

### **3.1. Introduction**

This chapter will outline how the study was developed and executed. This will start with an overview of my epistemological and ontological standpoint. Later, drawing on relevant literature, the development of the project, justification for the research design and consideration of how this approach would enable me to fulfil the aims of the research will be debated. Limitations of the research approach are acknowledged. Finally, quality, reflexivity and ethical considerations will be discussed. Due to the integrated nature of the discussion, it is important to highlight, at this early stage, that a narrative interpretive approach was adopted, using audio diaries and telephone interviews as data collection tools.

### **3.2. Philosophical standpoints and research paradigms**

The way in which research is carried out is ultimately shaped by a humanly constructed set of beliefs, or paradigm (Guba 1990). Denzin and Lincoln (2013, p26) describe this as a 'net' containing four things: ethics (also known as axiology), ontology, epistemology and methodology. Naturally one's own background, ideas and feelings influence how we view the world, i.e. our ontological self.

#### **3.2.1. Ontological self**

I came to nursing after a ten-year career in administration and building society work. I recognise that my own theories or epistemologies of professional behaviour were shaped by the rigidity of the building society regime. The focus on excellence in customer service and presenting the corporate image were well ingrained into my psyche. This manifested itself in a belief that being in control equated to professionalism, a link identified in healthcare literature, (Hershberger et al. 2010; Ghadirian et al. 2014) and ethics (Dehghani et al. 2015). Interestingly self-control has been identified as a way of overcoming feelings of inferiority (Brett 1992) to which I can be prone. Indeed, my personal ontological reflections have led me to conclude that I have tried to be 'better' by being in control and following rules, hence

my initial interest in the difference between my approach to professionalism and that of others. This was probably the first component in the incremental involvement of my area of research interest and the starting point for the professional doctorate journey.

Children's nursing was a conscious career change, triggered by two hospital admissions of my daughter and a desire for a more worthwhile career. I found being a children's nurse a difficult balance between being caring and compassionate whilst remaining in control and avoiding excessive emotional involvement, a commonly documented dilemma (O'Neill 1998; Gray 2009 a & b; Cargill 2014). I had been a parent of a hospitalised child, so it was sometimes difficult to separate my own experience from that of the child's parent, particularly if the child was a similar age to my own. I recognised, therefore, that this might also be true of other nurses, particularly those working in highly emotive environments. This added a further facet to my interest. So, I was starting to think about a combination of professionalism, self-control, emotional labour and nurse-parent relationships, demonstrating how the ideas for this thesis have evolved over my clinical career.

Whilst a student nurse I enjoyed the health visitor placement and took this pathway 3 years post-registration. This gave me the opportunity to pursue my career without the daily challenge of controlling my emotions. Health visiting was easier because the children were not clinically unwell.

Nonetheless many families were in dire need and at the beginning of my health visiting career I was occasionally tempted to visit outside of working hours or provide practical assistance from my own resources. However, I recognised that this could be a very 'slippery slope' (Melia 2014), particularly as I lived and worked in the same town, a difficulty which is highlighted by Baca (2011). I overcame this by imagining a rigid line between us which should never be crossed. I feel that this was helpful and necessary while I was inexperienced at managing long-term relationships with families.

However, I noticed that I became more skilled at being a professional family visitor as I gained more experience. So, the professional 'line', although ever-present, was a 'framework' upon which more instinctive and subtle approaches were built. Thus, the facet of 'long-term' nurse-parent

relationships was added to the 'pot' of my interest; and became a further building block for this thesis.

My rather rigid approach to work and professional relationships resurfaced somewhat when I became a nursing lecturer. The formality of the school of nursing at that time was perhaps underpinned by the relatively recent, wholesale, entry of nursing to higher education at undergraduate level and the long journey to becoming recognised as a profession. I often had the feeling that the 'school' was striving to justify its worth to the wider university. So, although I felt anything but inferior in the company of my nursing lecturer colleagues, I did feel inferior in the context of the university. However, the structure of semesters, curricula, modules, timetables, lesson plans and the general order of academic life, underpinned by regulations which I could follow, gave me a feeling of security and an opportunity to prove my worth by following the rules and keeping to the 'plan' for the lesson/day/semester.

Having worked in the university for nine years I sought a new challenge and was appointed as education and research lead at a Children's Hospice (CH), which had been one of my link areas. I was part of middle management rather than the clinical team, so I had the opportunity to observe the nursing team as something of an 'outsider'. The main thing I noticed was how different the nurse-parent relationships appeared in comparison with my own experience. I appreciated that the philosophy was to provide a 'homely' environment but the interactions I observed seemed very relaxed and social. Staff were very tactile with parents and each other at all times, not just those involving distress. This led me to revisit my thoughts on nurse-parent relationships that spanned significant periods of time, as well as the emotions involved in caring for children. I wondered how the hospice nurses coped with the emotions involved in providing long-term palliative care when their relationships with parents appeared so close. These musings were, of course, based on the experience of working at just one hospice. I wanted to explore this further. So, a number of facets of nursing which had interested me over my career combined to formulate the research project presented in this thesis.

This ontological exploration was a fundamental part of starting to develop reflexivity in data collection and analysis. It was also vital in helping me to recognise that to formulate an epistemology I needed to put aside rigid viewpoints, otherwise I would not be open to learning about different ways of managing nurse-parent relationships and I would stifle the voices of my participants.

### **3.2.2. Epistemology**

Epistemology is a branch of philosophy dedicated to answering the question of 'what is knowledge?' There are multiple philosophical positions, and none provides the definitive answer (Martin 2010). Views on what counts as knowledge are important because this determines what a 'field' knows about its own area of practice (Pallas 2001). Nursing knowledge encompasses more than the factual, which is why it is often termed the 'art and science of nursing' (Peplau 1988a). Polanyi's original idea of personal knowledge (1958) and later the tacit dimension (1966) was used by Carper (1978), and more recently Thorne (2020), who described individual tacit ways of knowing in nursing. So, it can be argued that much of the art of nursing is based on what is referred to as posteriori knowledge, i.e. knowing based on sense-experience (inductive reasoning). However, philosophers such as Plato favour the view that 'real' knowledge is 'priori' i.e. that which is not dependent on sense-experience (deductive reasoning). Others argue that posteriori knowledge is equally valid; it is merely established differently (Lacewing 2008). Furthermore, there is an argument that the two are closely linked, as posteriori knowledge often verifies a priori proposition (Tahko 2008); for example, an experienced nurse who has a 'feeling' that a patient is about to deteriorate before they exhibit any measurable clinical signs. This might be based on posteriori knowledge from previous experiences which have been assimilated to produce a 'gut' instinct whereby the nurse anticipates the priori or scientific presentation of the patient's condition. Others may argue that this is merely priori knowledge whereby the experienced nurse can detect subtle clinical indications seconds before the event.

In terms of managing relationships with parents, a nurse may be mindful of applying professional regulations or guidance to a situation but due to the

individuality of the nurse, the situation, the relationship and circumstances, it is very unlikely that 'scientific' or priori knowledge will be the main source of knowledge used. It is more likely that posteriori knowledge from a range of professional and life experiences will combine to form their personal approach to managing nurse-parent relationships. So, this research study aims to explore the inductive reasoning which enables children's nurses to formulate their approach to interactions with parents in the hospice setting.

### **3.2.3. Constructing a theory to explore practice**

It is important that the theoretical considerations underpinning a research study are clear as this demonstrates that logical decisions were made when selecting frameworks and tools (Carter and Little 2007).

This study sought to explore the individual inductive, emic reasoning and approach of CH nurses in relation to their relationships with parents, i.e. by gathering data from a range of multiple realities or 'life-worlds' (Galvin and Holloway 2015) and bring these together to form an overall understanding. Therefore, it was necessary to explore the nurses' experience and perspectives within that context and at a particular time, to gain this understanding (Balls 2009). A qualitative approach was therefore appropriate for this study.

Specific areas of interest arising from the literature review (particularly Section 2.7 which focused on the nurse-parent relationship) were managing emotional labour and maintaining professional integrity in the CH setting. However, to facilitate the emic stance of the research, the approach to collecting data (discussed in Sections 3.4.8 – 3.4.10. below) did not specifically direct participants to these areas of their relationships with parents, thus allowing the participant voices to shape my understanding. Moreover, this meant that rather than starting with a framework or theory, which would shape the methodology and methods, this would be introduced after the data collection and analysis phase to help make sense of the data (Chapter 6).

The initial protocol was refined through consultation with professional stakeholders. Section 3.3. outlines this.

### **3.3. Engagement with others during the planning phase**

Patient and public involvement in the development of research design is an excellent way of using the expertise of those who have personal knowledge or experience of a research topic (Snodin et al. 2017). It is an emerging feature of contemporary research and relates to citizenship, public accountability, and transparency (Morrow et al. 2012). Many research funding bodies now expect co-production of research design (National Institute for Health Research (NIHR) 2012 & 2019) and the development of this now extends to patient and public involvement in data collection, analysis and service-user controlled research (NIHR 2010). Stakeholder engagement in research design is also starting to appear in healthcare literature and is recognised as best practice (Boaz et al. 2018).

To develop my own ideas for the project I consulted with a number of stakeholders who were identified through my contacts at a local CH. Meetings took place to discuss the most recent version of the protocol, to ask for constructive criticism on the topic and the proposed methods. The protocol was continuously updated to reflect valid feedback from the stakeholders.

Between April 2017 and June 2017 discussions, which would reflect strategic and organisational perspectives, took place with:

- A Director of Care at a CH
- An experienced children's nurse currently working at a CH
- A social worker responsible for community services at a CH
- A former CEO of a CH

Arrangements were also made to meet with the father of a child who had been cared for at the local CH. He seemed keen to participate but cancelled our meeting twice, at short notice. Given the emotive nature of the topic and the fathers' circumstances I did not pursue this.



All professionals mentioned boundaries and emotional labour as issues for nurses working in CHs and highlighted the uniqueness of the environment. The former CEO particularly highlighted that the philosophy of CHs and the definition provided by Together for Short Lives (TfSL) make it clear that the care of the whole family becomes the responsibility of the nurse in a way that is very different from other settings. He acknowledged that much of the emotional support given in CHs is delivered by family support workers, who have counselling skills and social care backgrounds, but stated that it is inevitable that this work will become part of the nurses' role as they are caring for the child (and sometimes the family) on a 1:1 basis throughout the shift. He expressed concern that there is very little guidance given by CPC organisations such as TfSL or professional bodies on how nurses should manage care when the whole family is the 'patient'. He was aware that NMC and RCN guidance would apply but felt that in complex, emotive situations it was reasonable to assume that palliating the whole family would present challenges.

The hospice social worker was a valuable source of ideas and her articulation of why it is so difficult to achieve balance in long-term relationships with families was in line with my own thinking. She was very interested in professional boundaries. She saw them as a slightly movable entity depending on the circumstances. This discussion and that with the hospice nurse was helpful in improving the inclusion/exclusion criteria, particularly the period of employment and length of relationship with families. In addition, suggestions were made in relation to framing the guidance for the audio recordings, i.e. more of a 'tell me the story of your day' approach rather than asking about challenges. I had been struggling with wording in the participant guidance, initially believing that I needed to ask participants to talk about challenging situations to elicit data which would answer my research question. It felt like a risk to not explicitly seek out nurse-parent situations which the nurse found difficult. However, I realised that the felt extent of challenges would vary between participants, even within similar situations. Furthermore, the participants would be experienced in hospice nursing and this may mean that they would not necessarily see tricky situations as a

challenge in the same way that an inexperienced nurse may. Focusing on 'challenges' would be likely to skew the data (and subsequent findings) to instances where participants considered their management of an interaction to be sub-optimal. Therefore, I felt I needed to take a calculated risk of less prescriptive participant guidance and allow the participants to outline an ordinary day spent with a family. Inevitably this meant that some superfluous data were collected but I felt this was preferable to unduly influencing the participants' voices.

Although the changes made following stakeholder consultations were subtle, these interactions were invaluable in confirming the importance of the focus of the study and in refining the approach. Collaborating in this way also brought the project to the attention of senior staff at the hospice where I hoped to conduct the pilot study.

### **3.4. The study design and process**

#### **3.4.1. Research Question and Aims**

##### **The research question:**

How do children's nurses working in hospices manage emotional labour and professional integrity in long-term relationships with parents?

##### **Aims:**

To develop an in-depth understanding of how children's nurses manage long-term relationships with parents in the children's hospice setting.

To develop an in-depth understanding of how children's hospice nurses maintain professional integrity whilst providing long-term practical, emotional, social and spiritual care to parents.

To explore the coping strategies and protective factors used by children's nurses to manage emotional labour whilst working in the children's hospice setting.

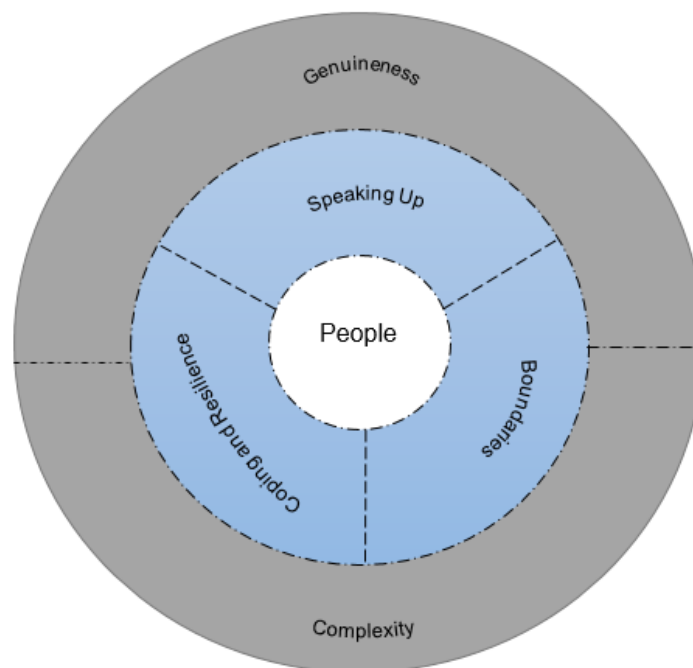
### 3.4.2. Definitions of concepts

It is important to define the concepts being explored by the study in order to be clear about what is being studied and to avoid ambiguity as much as possible.

#### 3.4.2.a. Professional integrity

Most definitions of professional integrity in nursing refer to moral values and beliefs. However, Tyreman (2011) states that although integrity relates to the personal values and beliefs of the individual, in healthcare this relates more closely to the professional community the individual is representing and the basis on which they form their identity. Nursing models of professional integrity appear to be largely absent from the literature. However, Blowers (2016 & 2018) provides one based on her work with students, mentors and lecturers (Figure 3.1).

**Figure 3.1: Blowers (2016) Model of Professional Integrity**



### 3.4.2.b. Emotional labour

The seminal definition provided by Hochschild (1983) (Box 3.1) was useful in helping me to identify and explore instances where participants were alluding to it and to later group participant thoughts, behaviours and coping strategies for managing emotional labour.

#### **Box 3.1: Hochschild's (1983) Definition of Emotional Labour**

*Emotional labour requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others- in this case, the sense of being cared for in a convivial and safe place. This kind of labour calls for a coordination of mind and feeling, and it sometimes draws on a source of self that we honour as deep and integral to our individuality... I use the synonymous terms emotion work or emotion management to refer to these same acts done in a private context where they have use value.*

*(Hochschild 1983, p.7)*

Hochschild (1983) also explained that emotional labour causes negative consequences for individuals and organisations such as emotional inactivation stress, physical exhaustion, emotional exhaustion, and absenteeism.

### 3.4.3. Selecting a Methodology

Section 3.2.3. justifies the qualitative approach and a number of qualitative methodologies were considered to support data collection and analysis for this study. These evolved as my ideas were shaped by reading about the topic, related concepts and methodologies, discussion with stakeholders and my supervisors. The process of exploring and rejecting other approaches is presented in Appendix 2. The justification for choosing a narrative interpretive approach is provided below.

#### **3.4.4. Narrative interpretive approach**

Narrative is an overarching term that encompasses longitudinal personal and human dimensions of experience and takes account of the relationship between individual experience and cultural context (Clandinin and Connelly 2000). Therefore, it was suitable for exploring nursing practice within a particular environment of care. This methodology involves the collection of stories to help researchers understand the lived experience of individuals, their thinking, actions and reactions (Ollerenshaw and Creswell 2002; Gray 2014). Essentially the story being told by the participant is their own contextual temporal sequencing, i.e. within a time span, often linking the present to the past and the future (Holloway and Freshwater 2007). This helps the researcher to assemble a holistic view of the participant's world (Holloway and Jefferson 2013) which was in keeping with my study aims. Further, Joyce (2015) claims that a narrative approach is particularly well suited to nursing research, especially that which seeks to explore the nurse-patient/client relationship.

Narrative research can be carried out using a variety of approaches. These include life histories, life incidents, storytelling, autobiography and biography (Letherby 2003). The particular approach suggested during stakeholder consultation of 'tell me the story of your shift' seemed to suggest that storytelling would be a good means of 'teasing out' the complexities of interactions between nurses and individual parents. In fact, this is really the only narrative approach which would allow the participant to focus on a specific short time span (a shift). Life incidents also relate to short time span stories, but these are defined as life changing events (Denzin 1989), so unsuitable for the project as I was aiming to explore the participants' ordinary daily experiences. Another possible approach would have been life histories as these can include particular events or experiences framed within the whole life context. However, although a nurses' whole career will have influenced the way they interact with families, the focus was on a particular shift rather than asking them to specifically consider how previous experiences and events had shaped their approach.

Storytelling is an everyday experience and involves reflection (Creswell 2015). Reflection is a familiar concept in nursing practice, so engaging in this research may have been useful for participants. Indeed, formal reflection is an NMC revalidation requirement (NMC 2017) and therefore stories told by participants while taking part in this project could be used for this (as noted in the participant information sheet - Appendix 3)

Narrative is an interpretive approach in the qualitative research paradigm (Joyce 2015). An interpretive approach is one in which the findings are the researchers' representations of how others present their stories (Geertz 1973). Therefore, this seemed appropriate to gather an understanding of how CH nurses manage long-term relationships with parents. This thesis will present analysis of individual perspectives against the backdrop of stories from practice (Chapter 4) followed by analysis of themes which are common to all, or the majority of, participant stories (Chapter 5). Including the stories within the thesis keeps the participants' perspectives, practice and strategies at the centre of the work. Possible disadvantages of the interpretive approach are that my interpretations are just that, interpretations. Other researchers may interpret the data differently and/ or choose different words or analogies to represent the same understanding.

#### **3.4.5. Research settings**

The settings from which children's nurses were invited to take part comprised one CH site in South Wales (feasibility pilot) and CH sites throughout the rest of the UK (main study). Ultimately participants for the main study were recruited from CHs in England.

#### **3.4.6. Sample**

A small number of participants are usual and acceptable in qualitative studies and particularly in narrative analysis where stories can be used to highlight the culture, complexities and contradictions in organisations (Gray 2014). The major consideration is that the sample size creates enough in-depth, textually rich data to answer the research question (Joyce 2015). Larger sample sizes are necessary if the participants are from various groups, e.g.

doctors, nurses, patients, rather than one homogeneous group (Holloway and Freshwater 2007) as is the case with this project.

Purposive sampling is most often used for narrative studies (Silverman 2013). This involves recruiting a sample from a particular group of people that have shared characteristics, experiences and understandings. For the pilot study a purposive sample of two children's nurses was recruited. The pilot study is outlined in Appendix 4 together with posters presented at local and national conferences. For the main study a purposive homogeneous sample of 6 children's nurses was recruited using the inclusion/exclusion criteria in Table 3.1. The nurses were asked to discuss episodes of care which occurred either as part of day or short-break care provision. Although by implication this would exclude EoL care I gave explicit instructions that shifts involving EoL care should not be included.

<b>Table 3.1: Participant inclusion and exclusion criteria</b>		
<b>Participants</b>	<b>Criteria for inclusion</b>	<b>Criteria for exclusion</b>
Registered children's nurses currently working in a CH setting (n=2) from feasibility pilot site plus 6 for the main study from other UK sites N.B. either with or without an additional specialist palliative care or related qualification, e.g. symptom control.	Have worked in the hospice environment for a minimum of four years. Have worked as a registered children's nurse in another clinical environment for at least one year prior to commencing employment in CH	Mental health or learning disability qualification (as possessing other qualifications may alter the way in which registered nurses manage their relationships with families – thus adding attributes which may not be present in those who do not have these qualifications)

### 3.4.7. Recruitment

The recruitment process was as follows:

- Gain approval from the organisation via gatekeeper or committee
- Distribute letters and participant information (Appendix 3)
- Receive expression of interest
- Dispatch consent forms (Appendix 5a & b)
- Receive signed consent forms

- Send welcome email with full guidance for completion and transmission of audio diaries (Appendix 6)
- Participant to complete a test audio recording and transmit to researcher, to ascertain quality and ability to use equipment.

For the main study sites, permission to recruit was sought by emailing an overview of the project to hospice Directors of Care or equivalent. Occasionally the Director of Care granted permission to proceed but the majority (n=8) referred me to a research ethics/clinical governance committee to seek approval. Following approval administrative staff would distribute letters to all qualified nurses enclosing the participant information sheet (Appendix 3). In addition to information on the study, a flow chart was provided which helped the nurse establish their eligibility.

The number of individuals who eventually agreed to participate totalled 9 with the target number of 6 producing data. The circumstances leading to recruitment of excess participants was because after recruitment, and before submission of the first audio diary, one participant needed to take time off work to care for a sick relative, and the other two stopped responding to emails and phone messages. Therefore new participants were recruited to replace them.

#### **3.4.8. Data Collection**

Bell and Waters (2014) state that narrative research data collection methods should firstly allow the storyteller to structure their story, with the researcher asking follow-up questions. This appealed to me because I wanted to limit my influence on the way in which participants told their story before I questioned them. Allowing participants to tell the story of a suitable shift (one involving day or short-break care) in a timely manner was challenging due to the unpredictable nature of nurse/family allocation. A solution may have been for participants to contact me when a suitable shift had occurred, and an interview arranged to hear the story followed by questions. However, this would be reliant on mutual availability, so the story may have been told some weeks later, risking recall bias (Althubaiti 2016).



Contemporary technologies allow information to be relayed instantaneously so various technological solutions for relaying the story of the shift from participant to researcher were considered. The idea of audio diaries followed by telephone interviews arose after reading about narrative research, thinking about the aims of the project and considering the benefits and drawbacks compared to other narrative methods. The methods chosen were selected to provide the best fit between a robust approach to eliciting data which were likely to answer the research question, managing the number of participants, geographical spacing of participants and constraints imposed by time due to part time study/full time work commitments. Discussions with stakeholders, who were working in health or social care roles at CHs, about which methods would fit best with participants, confirmed that the audio diary and telephone interview approach outlined in Sections 3.4.9 and 3.4.10. would be acceptable. Moreover, the feasibility pilot evaluation confirmed their useability.

The six main study participants were asked to complete two audio diaries, each of which were followed by a telephone interview. Although six participants were recruited not all were able to complete two audio diaries and telephone interviews. The timeline for recruitment of participants, start and end of data collection is shown in Table 3.2.

**Table 3.2: Recruitment and data collection timeline**

Pseudonym	Date recruited	No. audio diaries	No. telephone interviews	Time between recruitment and 1st audio diary	Date 1st audio diary sent	Date data collection completed	Duration of data generation
Alex	14.01.19.	2	2	2 months	Mar 19	Jun 19	3 months
Chris	15.02.19.	1	1	10 months	Dec 19	Jan 20	1 month
Les	07.06.19.	1	1	4 months	Oct 19	Nov 19	1 month
Jo	19.06.19.	1	1	3 months	Sep 19	Oct 19	1 month
Ashley	10.07.19.	2	2	1 month	Aug 19	Jan 20	5 months
Patrick	13.07.19.	2	2	3 months	Oct 19	Jan 20	3 months

Audio diaries were between 8 and 33 minutes in duration. Telephone interviews lasted between 22 and just over 54 minutes. The length of audio

diaries usually influenced the length of the telephone interviews, i.e. more questions generally arose from the longer audio diaries and participants who had recorded longer audio diaries were usually more talkative. There were instances where a participant was very succinct in their audio diary but raised complex issues which required further exploration.

### **3.4.9. Audio Diaries**

Audio diaries for this study were recorded on the participant's mobile phone, if they owned one and were able/happy to use the audio recording function. Diaries are an established data collection method which make what is implicit to the participant explicit to the reader, thus aiding in-depth understanding (Thomas 2015). Audio diaries are becoming more widely used in social science disciplines (Crozier and Cassell 2016) and have advantages such as capturing sense-making in the moment (Monrouxe 2009). Another advantage is that they have been found to lead to lower levels of attrition because they are easier to complete (Siemieniaki 2017; Markham and Couldry 2007). Audio diaries have previously been used to explore workplace phenomena (Crozier and Cassell 2016) and specifically in narrative research with healthcare professionals (Greenhalgh et al. 2005; Monrouxe 2009; Joyce 2015), so my selection of this method seemed reasonable.

The use of mobile phones is an emerging means of facilitating the collection of audio diaries (Siemieniaki 2017) and as it is an item familiar to most people it is likely to be more engaging (Worth 2009) than unfamiliar equipment. Any participant who did not have a mobile phone suitable for making an audio recording or did not wish to use their phone for this purpose would have been issued with a Dictaphone and micro-cassettes. Ultimately this alternative was not sought.

Audio diaries as a data collection method is not without its critics. Latham (2003) suggests that the recording is a performance and therefore not authentic. This was a consideration because participants were aware that I was a nurse, so they may have performed in a way that was compliant with professional expectations. However, Crozier and Cassell (2016) stated that

this is no different to representations made in interviews. Furthermore, they suggested that minimal cognitive processing takes place before making a recording, whereas other methods such as interviewing rely entirely on retrospective accounts (Kenten 2010). Another disadvantage is the absence of non-verbal communication such as facial expressions (Denzin and Lincoln 2000). However, Sacks (1992) stated that although it is considered ideal to study all aspects of a participants' response, such 'completeness' is a myth as there is no such thing as complete data any more than there can be a perfect transcript.

Those who have compared audio diaries with written accounts suggest that although audio diary entries are less structured, they include a deeper reflective element (Markham and Couldry 2007) and were therefore likely to produce 'stories' which really demonstrated how children's nurses think about the management of long-term relationships with parents and the affective responses to interactions, rather than talking about interactions in an abstract way.

Although audio diaries have been identified as preferable to written diaries, participants have occasionally identified difficulties such as finding a quiet/private space to make the recording, one sidedness of the 'conversation', confidentiality concerns and feeling conscious about talking into the recording device (Williamson et al. 2015; Crozier and Cassell 2016). However, positives such as the convenience and flexibility of the approach (Worth 2009) together with the therapeutic and reflective value are said to outweigh negatives (Williamson et al. 2015).

Secure transmission of the audio diaries was a source of much discussion between myself and my supervisors and a condition of School Ethics Committee approval. Advice was sought from within the School, other Schools and central departments of Cardiff University. Arrangements such as password protected email attachments were suggested but this felt complicated and required technical expertise. Ultimately a discussion during my annual review revealed the solution, a mobile phone application offering 'end to end' encryption, 'WhatsApp'. This is commonly used and

straightforward. School Ethics Committee approval was given for the use of WhatsApp. Participant guidance for the audio diary had already been formulated and approved. So, instructions on how to record and transmit using WhatsApp were added (Appendix 6).

The distance of the researcher from the gathering of data in the audio diary approach is said to be an advantage because there is minimal researcher influence on participant accounts (Monrouxe 2009). Therefore it elicits a more neutral account compared with constructing a story in response to questions (Holloway and Jefferson 2013). However, this means that audio diaries place the frame of reference firmly with participants, so guidance is needed (Hislop et al. 2005). This required careful consideration. The aim of the guidance was to promote collection of data that fitted the aims of the study but did not constrain it, so ideas and concepts that had not already occurred to me were not stifled (Crozier and Cassell 2016). Guides can also encourage participation if there is uncertainty about what is and is not relevant (Boyd et al. 2004). My guidance included some suggested prompts (Appendix 6) to aid the participant in starting their recording as this has shown to be helpful, particularly in the initial phase (Worth 2009). However, the guide encouraged participants to speak about whatever come to mind when thinking about their long-term relationship with the parents, as trying to make diaries more formulaic could decrease the richness of the data (Mazzetti and Blenkinsopp 2012).

To ensure that the instructions were clear and to test the efficacy of the technology the feasibility pilot participants completed an evaluation of using audio diaries, ease of using WhatsApp and the clarity of the guidance (Appendix 7). Following collation of the feedback and my own personal reflection on the pilot some minor amendments were made to the guidance.

Participants were asked to make recordings in private, as soon as possible after the shift. Participants could utilise the journey home, if they travelled alone in a car, providing this did not compromise their safety. This minimised the time commitment and was similar to the 'doubling up' approach used in the Williamson et al. (2015) study where participants made their recordings

whilst breastfeeding their babies. With regard to maintaining confidentiality very clear instructions about the care of the recording device were given. However, one could argue that the risk involved is no different to that posed by the loss of a handwritten diary. All recordings were listened to at the time of submission. This gave me an opportunity to check the quality and completeness of the recording. Participants were asked not to delete the recording from their phone until I had confirmed that it had been received and saved.

Each participant was asked to complete two recordings relating to two different families over 1 – 3 months. The justification for requesting two recordings over this duration related to giving participants sufficient opportunity to select families whom they have cared for over the requisite three years or more. The rationale for asking participants to select two different families was to give a sense of how they may interact differently depending on family dynamics, circumstances, and their relationship with a particular family. This approach has similarities with case study research in that the aim is to gain an in-depth understanding (Yin 2014) by focusing on a small number of interactions over a significant but manageable duration.

Some researchers have used routine participant reminders to ensure completion of audio diary recordings (Boyd et al. 2004; Crozier and Cassell 2016). However, as I had asked that participants make a recording when an appropriate situation occurred (rather than specific junctures) this was not suitable. So, I waited until the end of the first month following recruitment to check in. Further reminders were used at later intervals and this was carefully managed as it would be unethical to apply undue pressure (Thomas 2015).

#### **3.4.10. Diary interviews**

Diary interviews were undertaken by telephone as soon as possible after receipt and transcription of each audio diary recording. This method has been shown to be useful for clarification of audio diaries and deeper exploration of topics raised by participants (Kenten 2010; Baumbusch 2010), particularly for sensitive topics (Bell and Walters 2014). In fact, it has been

suggested that diaries followed by interviews, the questions in which are informed by the diary content, are an approximation of participant observation (Zimmerman and Wieder 1977).

Oltmann (2016) highlights the increasing popularity of telephone interviews over the last 3 decades. Nevertheless Holt (2010) noted that the use of the telephone for production of narrative data, had at that point, not been sufficiently explored. Some consider this to be an inferior method of data collection (Sturges and Hanrahan 2004) due to the absence of body language cues, whilst others such as Yin (2014) state that the non face-to-face aspect of this method can help participants feel more relaxed and speak more openly. Lechuga (2012) concluded that successful qualitative interviews were not defined by whether the interviewer and interviewee were in the same room. Ultimately, literature which discusses face to face versus telephone interviews is scattered across disciplines, so Oltmann's piece (2016) synthesised evidence to provide an explicit and comprehensive framework. I used this to make a decision about whether this was an appropriate method for my study. The framework reflects both the interviewer and the respondent context as shown in Table 3.3.

<b>Table 3.3: Interviewer and Respondent context for Telephone interviews</b>	
<b>Interviewer context</b>	<b>Respondent context</b>
Time and financial costs Geographical distribution of respondents Sensitive or controversial topics Technology problems Interviewer safety Note taking Interaction effects Non-verbal language and cues	Scheduling Respondent anonymity Privacy / invasiveness Stigmatized/ marginalized groups Sensitive or controversial topics Respondent empowerment
(Oltmann 2016)	

Oltmann (2016) stresses that neither face to face nor telephone interviews are superior to the other when considering either the interviewer or the respondent context. Both have strengths and weaknesses. She recommends that researchers select the method most appropriate and useful for their project, based on which of the contextual components are most important and relevant. The framework is a means of reviewing and considering both

contexts enabling the researcher to make a thoughtful, defensible selection. Scoring my own project against the criteria in Tables 3.4 and 3.5 (shaded in grey) shows that telephone interviews were an acceptable choice.

<b>Table 3.4: Interviewer context (Oltmann 2016)</b>		
<b>Key – shaded area = applies. Non shaded = neutral response</b>		
<b>Components</b>	<b>Face-to-face (F2F) mode</b>	<b>Telephone mode</b>
Time and financial costs	Usually intensive; travel may add to costs	Can be less time intensive than F2F; lower costs (no travel)
Geographical distribution	Often limited geographically to local area	National and international access possible and easier
Sensitive or controversial topics	May be difficult in F2F; potential to be embarrassing or awkward	May be less awkward than F2F
Technology problems	Less likely to have problems, except with recording device	Calls can be dropped; possible recording problems
Interviewer safety	Can be endangered depending upon location and time of meeting	Low danger; interviews can be made from office, home, or other location as appropriate
Note taking	Can be obtrusive; can capture non-verbal language and cues	Can be done unobtrusively; may present logistical problems juggling multiple items
Nonverbal language and cues	Usually very rich; can include dress, body language, mannerisms, etc.; more data to be interpreted; can be misinterpreted	Most types unavailable; can note pauses, hesitations, etc.; less information, but less potential bias and misinterpretation
Overall score = Telephone = 4, Face to face = 1, neutral = 2		

<b>Table 3.5: Respondent Context (Oltmann 2016)</b>		
<b>Components</b>	<b>Face-to-face (F2F) mode</b>	<b>Telephone mode</b>
Scheduling	Participant may feel pressure to be available; may have lower dropout rate	Easier to reschedule via telephone; less social pressure; easier to avoid time conflicts; easier to cancel
Respondent anonymity / confidentiality	Difficult to hide identity from interviewer; anonymity dependent on interviewer integrity and data protection; can decrease disclosure	Perception of higher anonymity; can lead to more disclosure
Privacy / invasiveness	Can be invasive to participant (often in their home/ office); F2F can be less invasive than technology; cannot hide non-verbal language	Can either reduce or increase invasiveness and surveillance fears
Stigmatized / marginalized groups (N/A)	May be more or less difficult for marginalized individuals, depending on social pressures and cues	By increasing distance from interviewer, may improve responses from marginalized individuals
Sensitive or controversial topics	May be uncomfortable or embarrassing; may conform to	May ease discomfort or awkwardness; may improve accuracy of reporting

	social expectations; may under-report	
Respondent empowerment	Can see and respond to interviewer; social pressure (potential loss of face) more evident in F2F	More control; easier to reschedule; less chance of loss of face
Overall score: Telephone = 4 , Face to face = 0, Neutral or N/A = 2		

At the start of each telephone interview, I clarified that I was asking the questions as a researcher rather than a nurse. So, I might ask the participant to explain something which may be obvious to a nurse but needed to be explicit for the purposes of the study. For example, in relation to nursing practice or procedure, particularly facets which were specific to the CH environment or philosophy of care. However, it would be impossible to ever truly put aside one's intrinsic professional knowledge, so there was still a risk of implied/shared understanding or assumptions which could impact the findings of the study. Another aspect of the telephone interview which I wrote about in my reflective diary was, having listened to the participants' voice and thoughts in the audio diary recording, I had the sense of slightly 'knowing' them before the interview took place. Whereas the first time they heard my voice was at the start of the telephone interview. I perceived this to be a potential 'inequality' in the relationship (in addition to the fact that they may see me as 'important' because I am a Senior Lecturer and a researcher), so I almost felt that I was obliged to put them at ease by engaging in some brief 'small talk' at the start.

The question schedule for the telephone interviews was based on the content of the audio diary and took several forms; to clarify my understanding, to clarify content and to explore an issue further. In some instances, new questions arose during the telephone interview, usually when the participant introduced a new topic or viewpoint relevant to the research question. Sometimes this new information related to the family discussed in the audio diary, perhaps during that or a previous visit to the hospice and sometimes the participant told a story about another family/situation to illustrate their point; essentially telling a story within the story. Therefore, the data became more than the sum of its two parts, as experiences with other families were



brought in by the participants. Occasionally I also asked for a participant's view on an issue raised by another participant. This was done in a general rather than specific way to ensure confidentiality.

Ultimately a greater amount of useable data were elicited from the telephone interviews (demonstrated by the pre-dominance of telephone interview extracts used in Chapters 4 and 5) compared to the audio diaries. However, I felt that the audio diaries were an excellent vehicle for helping participants focus on their relationship with a particular family and worked well as a 'conversation starter'.

### **3.4.11. Data Analysis**

#### **3.4.11.a. Introduction**

Data analysis is the process through which the gathered data are structured and organised, by identifying, labelling and coding (Joyce 2015). Narrative analysis can be applied to any form of textual data (Clandinin and Connelly (2000). A paradigmatic-type narrative inquiry approach was used in this project whereby stories were gathered for their data and categorised according to the common elements within and across the datasets. This is fundamentally different to narrative-type narrative inquiry which uses narrative analytical procedures to produce explanatory stories (Polkinghorne 1995). Simply put this means that narratives collected in this study were thematically analysed rather than constructing a new narrative or re-storying a narrative. Further the specific type of thematic analysis used is inductive, so the analysis was not shaped by a pre-existing theory but by my own standpoint, epistemology and disciplinary knowledge (Braun and Clarke 2013).

#### **3.4.11.b. Development of the approach to data analysis**

For a novice researcher a set procedure for analysis is recommended (Priest et al. 2002). So, I explored frameworks and found that features of narrative analysis can be the content, structure, language or the performative function (Grbich 2013). Joyce (2015) recommends that when selecting a method of analysis it must fit the aims and philosophical basis of the study. I felt that

analysing the structure of the story would not meet the aims of the research nor would analysing the performative/interactional aspects of the data, especially as for part of the data collection (audio diaries) there was no interaction between participant and researcher. To test this, I used an extract from the first audio diary and analysed it using two frameworks, i.e. Labov's structural model (1972), cited by Esin (2011), and Riessman's (2008) thematic model (Appendix 8). I compared these to ascertain which approach was most helpful in answering the research question and found that Riessman's worked best. In terms of fitting with the philosophical basis of the study the thematic approach allowed me to explore the content of the stories in a way which placed the participants' perceptions and interpretations at the centre. This also allowed me to identify themes within and across participants' accounts as described by Ayres et al. (2003)

When reflecting on the differences between the audio diaries where there was minimal researcher influence (apart from the guidance - Appendix 6), and the telephone interviews, where I was leading the interaction, and therefore influential (Sandelowski 1991); I wondered whether it would be better to analyse the audio diaries and telephone interviews separately, using different approaches, and then 'dove tail' these together for each participant. Combinations of models have been used in biographical narrative nursing research (Kelly and Howie 2007).

As stated in section 3.2.3 the epistemological approach to this project is a naturalist one, where participants describe their experience in their everyday working life, what happened, what they did at a particular time and what the experience meant to them. The typical questions used in a naturalist approach outlined by Esin (2011) allowed me to explore both the audio diaries and telephone interviews. Table 3.6 below demonstrates which 'what' questions would correlate with analysis of each group of data. Therefore, a single model of analysis was used. Further reading on this revealed that a naturalist approach is better suited to single rather than plural model analysis (Esin 2011) which supported my decision.

<b>Table 3.6: Exploring the ‘what’ of the data groups</b>		
<b>What questions (From Esin 2011)</b>	<b>Audio Diaries</b>	<b>Telephone interviews</b>
What happened?	x	
What experiences have people had?	x	x
What did people do at that particular time?	x	x
What does it mean to storytellers?		x

I continued to ponder whether I should analyse the audio diaries and telephone interviews slightly differently or at least how I could link each audio diary with the subsequent telephone interview. They were naturally connected due to the way in which the data were collected, i.e. the content of the audio diary informing the telephone interview questions. Serendipitously I encountered the work of Moran-Ellis et al. (2006) which demonstrated how to intermesh data collected in different ways by using an approach referred to ‘following a thread’; whereby each dataset is analysed and identified codes are followed up in the other dataset. This approach had previously been used to intermesh diary and interview data (McDonnell et al. 2016), so it suited my project and appeared to provide the solution I had been seeking. At this stage (June 2019) I had a complete data set from Alex and was awaiting audio diaries from other participants. Therefore, I used this time to explore the ‘following a thread’ approach.

Initially I returned to Riessman’s Thematic model as I had identified, in my comparison with Labov, that a thematic approach to analysis would allow me to answer the research question best. However, upon starting to work with a larger amount of data I found that Riessman did not offer sufficient clarity and detail to guide me. Therefore, I searched for a more detailed and useable model. I identified Braun and Clarke (2006) as suitable, particularly as their article describing the use of the model is aimed at novice researchers. As well as a six-step model, Braun and Clarke (2006) outline a 15-point checklist for good thematic analysis (Appendix 9). This was useful in helping me to use the model and provided a ‘recipe’ for theoretically and methodologically sound thematic analysis.

I had already familiarised myself with the data set, having transcribed all the audio diaries and telephone interviews myself, checked them for accuracy against the recordings, noted initial thoughts and read them several times. To ensure that data analysis was focused on the research question any unrelated material was redacted and set aside, referred to by Polkinghorne (1995) as narrative smoothing. However, relevant text surrounding the passage was retained to place it in context (Braun and Clarke 2006). Much of the redacted material related to nurses' views of parental coping strategies which will be respected by exploration and submission for publication elsewhere. Audio diaries required most redaction since their content was determined by the participant who, due to the flexible nature of the diary, sometimes strayed away from the focus. This had been identified as both a positive and negative feature of audio diaries, in that information that is irrelevant to the research question may be included, but elements of the participants' work which had not occurred to the researcher may be revealed (Williamson et al. 2015). Telephone interview transcripts were more closely aligned to the research aims as my questions specifically explored areas of the audio diaries which related to the management of nurse-parent relationships. Once redaction had taken place the transcripts were re-read again several times. Further redacted transcripts were double checked by re-reading the original full transcript, undertaking a 'blind' redaction and then cross checking against the first redacted version.

The next stage comprised of identifying codes in each audio diary and following up these codes in the subsequent corresponding telephone interview transcripts. Further codes, which were not present in the audio diaries, were also identified in the telephone interviews. Codes were allocated consecutive numbers as they appeared. Initial thoughts and my reflective diary were revisited once coding was complete to check if the codes were reflected in the initial impression of the whole. As advised by Saldana (2016) during the whole redacting, reading, coding, categorisation and theming process I kept a copy of the research question and aims near me to ensure that the focus of the study remained uppermost in my mind.

Codes were subsequently collated into categories with some codes being allocated to more than one category if the data extract warranted it (Braun and Clarke 2006). Categories were then grouped into themes for each separate audio diary and telephone interview pairing. These were documented separately and then amalgamated to an overall set of themes for each participant. I trialled this process with the first participant 'Alex' and was able to code, categorise and identify themes which were aligned to the research question and aims of the study. Having used this method for one participant I was confident that I could move forward with analysing other audio diaries and telephone interviews in the same way.

Unsurprisingly, due to the 'following a thread' approach, some codes, categories and themes appeared in the audio diary and arose again in the telephone interview, but others were confined to the telephone interview only. Ultimately more codes and categories were identified in the telephone interviews than the audio diaries, but this was somewhat inevitable due to the specific nature of the questions asked, the clarifying and prompting nature of the questions and the two-way nature of the interview versus the audio diary monologues.

To identify themes across the whole data set, I repeatedly moved back and forth between individual stories and the whole 'text' or data set. As well as identifying across story themes this iterative approach was useful in helping to represent the richness of the data set and the complexity of the experience (Ayres et al. 2003).

#### **3.4.11.c. NVivo 11**

I set out with the intention of using NVivo to assist data analysis and attended the training. However, I found that this stifled my creativity and I became more focused on identifying what should be coded and how, spending hours adjusting and readjusting nodes and their alignment with different parts of the text. Although a manual system does this in a different way, I found that the 'post it note' system made me less 'task' focused and gave me more time to think as I looked at the visual representation of the text, coding and themes as they evolved (Examples provided in Appendix 10). Nevertheless, NVivo

was used to store transcripts and the small amount of demographic data collected via the consent forms (Appendix 5a & b). This may be useful should I wish to undertake further analysis on the correlation of specific characteristics with particular themes.

### **3.5. Assessing quality in research**

Quality research produces evidence that is robust, ethical, withstands scrutiny and can be used to inform nursing practice (Holloway and Galvin 2017). Quality in qualitative research has long been debated, particularly in relation to narrative research (Bailey 1996). This is due to concepts, traditionally understood from the positive perspective, being applied to interpretive research. These paradigms are epistemologically divergent, so it is unsurprising that they are not necessarily transferrable. Many frameworks for ensuring quality in qualitative research have been developed over the last three decades. However, the seminal work of Lincoln and Guba (1985) is helpful in plotting a line between accepted positive concepts to those which can be applied to the field of interpretive research. For example, they proposed that internal validity be replaced by credibility, external validity by transferability, reliability by dependability and objectivity by confirmability. I have used some of the headings provided by Lincoln and Guba (1985) to structure this section of the thesis.

#### **3.5.1. Credibility**

To enable the reader to fully understand the research processes detailed descriptions of the research methodology, methods and analysis were provided in this chapter. These descriptions demonstrated that a suitable methodology and methods were selected to meet the aims of the research.

When discussing internal validity (referred to here as credibility) Norris (1997) noted that error and bias are important factors to consider and that steps should be taken to avoid these. I have attempted to reduce errors and bias by undertaking a systematic, analytical processes which included transcribing data verbatim, staying close to the participants' meanings and remaining aware of my own thoughts, feelings and existing preconceptions (Braun and Clarke 2006). Although a literature review was completed prior to data

collection this was not used to guide or structure themes. Further interpretative rigour (Forero et al. 2018) is attended to by the inclusion of substantial verbatim data to demonstrate themes and quotation of sections within context to ensure that I represented participants' meanings honestly (Taylor 2012).

Other factors which enhanced the research's credibility were my familiarity with the setting, topic area and prior knowledge of the context. While the potential disadvantages of a lack of objectivity were addressed by my open acknowledgment of the characteristics, experiences and values which I brought to the process.

Nevertheless, when analysing narratives researchers interpret stories which have already been internally interpreted by participants (Holloway and Freshwater 2007). Furthermore, as with all qualitative research, narrative data is open to a number of interpretations, which may lead to doubt about the credibility of analysis (Woods et al. 2002). Even when following a set procedure for analysis individual researchers may arrive at different conclusions about the same data set. However, responsibly conducted analysis that is in keeping with the data and its methods can be considered valid (Woods et al. 2002).

### **3.5.2. Transferability**

#### **3.5.2.a. Transferability within the study**

Due to the nature of the design and methods, thick descriptions were elicited and a range of in-depth data extracts generated. These extracts therefore provided a contextual richness and information specific to the individual participant. These are necessary for understanding individual stories, but it has been suggested that within story methods are less useful in the development of generalisations about experience drawn from across multiple 'cases' (Ayres et al. 2003). However, Ayres et al. (2003) also demonstrate how the paradoxical aim of transferability of qualitative analysis from within and across participants can be achieved in a range of study types, including analysis of narratives. This is achieved by repeatedly moving back and forth between individual stories and the whole 'text' or data set; in this case the

pairs of audio diaries and telephone interviews for each participant (which had been joined by the 'following a thread approach') and then combining these to arrive at themes for each participant and the amalgamated text of all audio diaries and telephone interviews. This identified a number of examples which were common to all or the majority of participants.

### **3.5.2.b. Transferability beyond the study**

This original research has contributed some new insights into a topic area which, whilst evident within the literature, has benefited from specific attention focused on the CH setting. Gill and Dolan (2015) discuss the importance of balancing claims of originality with realism about what has been achieved and in this thesis I have reported the particular findings of my research and tried to avoid any grand or unsubstantiated claims. However, it is possible that the findings may be transferable to other nurses working in the CH setting. The findings may also be transferable to other clinical areas where long-term relationships exist between children's nurses and parents. In terms of my own practice as a nurse educator the findings can be applied to educating a range of nursing students and preparing them for the demands of practice. This is explored in more depth in the discussion chapter where I discuss the impact of undertaking the Professional Doctorate on my practice.

### **3.5.3. Dependability**

Understanding of audio diaries was checked with participants during the subsequent telephone interview. Dependability was also checked during supervision via the presentation of a number of written up cases alongside data extracts and discussion of my reflective diary.

### **3.5.4. Confirmability**

Carefully planning and execution of the study was important in confirming the objectivity of the findings. It was likely that objectivity would be influenced by researcher bias either via pre-existing values or pre-conceptions about working in the CH environment. Minimising these influences is important and I attempted to do this via reflexive mechanisms. (discussed in Section 3.7).



### **3.5.5. Research Design Limitations**

Limitations of audio diary collection and telephone interviewing are that these methods do not reveal the participants' actions, only what they say they do and how they say they view their role. So, despite the close proximity (in time) of the audio diaries being recorded, it must be acknowledged that these may have been 'censored' for socially/professional acceptable accounts of behaviour. Furthermore, the period which elapsed between audio diary submission and the telephone interview could have led to participants verbalising slightly different views to those originally expressed, particularly if I probed a specific issue about which they felt unsure/uncomfortable or defensive.

Although substantial time was invested, the audio diaries and telephone interviews did not necessitate prolonged direct contact with the participants which may have affected the amount and nature of the information they shared with me (Charmaz 2004).

In this study the sample did provide rich data, but the number of participants could inevitably be seen to be a limitation of the research.

### **3.6. Reflexivity**

Reflexivity in the sense of acknowledging my own knowledge, values and bias together with how I may affect participant responses is important (Bryman 2016). I have endeavoured to demonstrate reflexivity throughout the work, both within the text and through inclusion of extracts from my contemporaneous reflective diary which are shown as footnotes. A final reflection is included in Chapter 7 which serves the purpose of demonstrating reflexivity right to the end of my Professional Doctorate journey.

Additionally, some of the main considerations are outlined here. In terms of the pilot, as a former employee of this CH, I was mindful that I may have pre-conceived ideas about what to expect from the diaries (both here and, in fact, from other CHs). It was particularly important to consider that my former employment status may influence participant responses, firstly because they already knew me and secondly because I was once in senior role there. I

decided early in the research design that the data collected from the pilot would not be part of the main study. This decision was validated by an entry in my reflective journal<sup>1</sup>.

The pilot was also useful in highlighting a point raised by Burgess (1984) of how participants can often assume researcher knowledge because they are of the same profession and have worked in the same or a similar area of practice. This was revealed by frequent use of acronyms or referral to common hospice practice, e.g. sitting down for lunch with families. This made me realise that I would have to ask the participant to explain such terms or practices during the telephone interviews. Clarification had to be carefully managed as halting a participant to provide an explanation could interrupt their train of thought. So, I usually made a note of it and came back to it later.

### **3.7. Ethics, Consent and Confidentiality**

#### **3.7.1. Ethics**

This project was undertaken within the Cardiff University Research Integrity and Governance Code of Practice (initially 2015, later 2019). The Research Governance Framework for Health and Social Care in Wales (Welsh Assembly Government 2009) was adhered to at the start of the project and later the UK Policy Framework for Health and Social Care Research (Health Research Authority 2017). This replaced the separate Research Governance Frameworks for each UK country with a single set of principles. However, no fundamental change to this project was necessary due to these new requirements.

CHs are independent, so NHS Research Ethics and Research and Development Committee processes did not apply. School Research Ethics Committee approval was granted in September 2017. Due to outstanding

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<sup>1</sup> Extract from reflective diary. 1.3.18. Second participant for pilot study recruited today. I know that both are reliable, so they are likely to engage and be diligent in their completion of the audio diaries. I've just realised that I have made a judgement about my participants based on my existing knowledge of them. If I am making judgements now it is clear that my pre-conceived ideas about them would influence my analysis and interpretation. I'm sure the pilot will be useful for feasibility purposes but this shows that my decision not to include the pilot data in the main study was the correct one.

issues of secure transmission of audio diaries and recruitment difficulties revisions were made with final approval being granted in September 2018. Approval for recruitment at individual sites was granted by an internal ethics committee, the Director of Care or the Executive Board.

Due to the emotive nature of caring for CYP with life-limiting conditions and their families it was possible that participants would become upset during data collection. Strategies to address this were to direct them to their hospice-based support systems e.g. internal clinical supervision, line manager, peer support and / or external clinical supervision provision. In instances of participant distress (occurred in the pilot but not the main study) I took care to maintain the role of the researcher rather than the nurse (Sheldon and Sargeant 2007). In addition, there was also a possibility that I would be affected by the scenarios described by participants. This did not occur, had it done so I would have sought support from my supervisors.

### **3.7.2. Consent**

Participant information (Appendix 3) was forwarded, by email, to those expressing an interest. Once positive confirmation was received, consent forms were despatched by post with an SAE, marked 'Strictly Private and Confidential' enclosed for their return. Two consent forms were required for each participant. One for the completion of the audio diary and one for telephone interviews and their recording. Participant consent for recording the diary telephone interview was also reconfirmed at the beginning of each telephone interview.

Participants were informed that they had the right to withdraw from the project at any time without giving a reason, up until the submission of the thesis and / or publication of the findings.

### **3.7.3. Confidentiality**

To maintain the flow of thought and allow participants to focus on the sense-making aspects of their recording I did not ask them to change the names of the individuals they were referring to. Pseudonyms, chosen by me, were allocated to children, parents and siblings immediately upon transcription

(Appendix 11). However, some ethics committees did request an alteration to the participant guidance, indicating that participants should change names of parents and children. Nevertheless, pseudonyms were allocated regardless of whether names had already been changed by the participant. The study sites are not identified. For confidentiality and to aid concentration and reflection I asked participants to record their audio diaries in private. Participants were asked to delete their audio diary as soon as I had confirmed receipt. If they chose to retain it for reflective purposes the 'How to complete and send your audio diary' document (Appendix 6) made it clear that it was their responsibility to ensure it was kept safe.

All participants were allocated an identification number and all data collected from individual applicants was initially labelled using this number. To ensure that confidentiality was maintained the list cross-referencing the participant number with the name of the participant was kept in a separate password protected folder. Identification codes were later replaced by pseudonyms. The allocation of pseudonyms was delayed until all participants were recruited to avoid the possibility of using the 'real' name of a latter participant for one recruited earlier in the study.

The consent forms (Appendix 5a & b) made it clear that in the unlikely event that any practice which was unsafe (that endangered the child/ family) or concerning (which compromised professionalism or negatively impacted on the nurse) was revealed, then I had a responsibility as a registrant, to act on this (NMC 2018) and inform the appropriate person at the study site. As well as professional body requirements there is also a legal responsibility to breach confidentiality in certain circumstances such as where the individual had given consent (achieved via consent forms in Appendix 5a & b) or when disclosure is necessary to safeguard the individual, or others. So, the Common Law Duty of Confidentiality also applied (DH 2007).

The University computer network was used to store all project information. My allocated section of the network is encrypted by a password, known only to me, and it is a secure network. In line with the Cardiff University Research Integrity and Governance Code of Practice (2019), the principles of data

protection were applied (Data Protection Act 2018) to the storage of non-electronic information. All non-electronic information was kept in private storage to which I am the only key holder.

### **3.8. Summary**

The purpose of this chapter has been to outline how the study was developed temporally and theoretically, underpinned by consultation with stakeholders. It began by outlining the approach and my ontological and epistemological standpoint. This was followed by the development of the project, justification for the research design and consideration of how this approach enabled me to fulfil the aims of the research. Finally, quality, reflexivity and ethical considerations were discussed. The next chapter will present data analysis for each participant.

## CHAPTER FOUR: INDIVIDUAL PARTICIPANT STORIES AND WITHIN STORY THEMES

### 4.1. Introduction

This chapter will introduce the six study participants, provide an overview of their clinical background and some demographic information. Themes are then presented for each participant <sup>2</sup> which are illustrated using extracts from the individual data set.

As recommended by Creswell (2016), each participant story is outlined before presenting the themes. During the writing of this final version and every draft of this and the next chapter I have continually moved back and forth between the transcripts, my coding and presentation of the findings, to ensure that the participants' voices are represented in a clear and authentic manner. Where there is ambiguity I have acknowledged this, particularly in instances where meaning has been interpreted but not specifically checked.

The six study participants (five females and one male), referred to throughout by the pseudonyms Jo, Chris, Les, Alex, Ashley and Patrick, were drawn from four different hospices across England. Three participants worked for the same organisation although these were split over two of the three hospices within the group. The ages of participants ranged from bracket 'C' (35-40) to bracket 'F' (51-60). The occurrences within each bracket are shown in Table 4.1.

<b>Table 4.1: Participant age</b>		
<b>Age bracket</b>	<b>Name(s)</b>	<b>Total number in age bracket</b>
C (35 – 40 years)	Jo	1
D (41-45 years)	Chris Les	2
E (46-50 years)	Alex	1
F (51-60 years)	Ashley Patrick	2

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<sup>2</sup> For participants who had told me two stories, early drafts presented the themes for each story separately whilst following the thread both from audio diary to telephone interview and from story to story. However, there were so many instances where the same themes occurred in Story One and Story Two that I felt that the analysis would be more coherent and meaningful if themes for each participant were presented rather than for each story.

The participants had worked at the hospice for a range of 4 to 32 years. Prior to this they had worked in a variety of areas (outlined in individual biographies) and been qualified for 15 to 34 years. The data collection period spanned March 2019 to January 2020.

#### **4.2. Alex**

Alex was dual qualified (adult and child). She had been a registered children's nurse for seventeen years and had worked at a hospice for eight years. Her previous clinical experience was in CYP orthopaedic and neonatal nursing. Alex undertook 'bank work' at the hospice before taking up a permanent position. She was attracted to the work by the formal and informal staff support offered there. Alex's adult sibling died in a hospice approximately 4 years before data collection took place. She was in her late 40s. Alex's stories are outlined in Box 4.1:

## **BOX 4.1: ALEX'S STORIES**

### **Story One**

Alex described caring for a child, Bridie, who had been resident for short break care. She had been caring for Bridie and her family for six years. Bridie was due to go home and her stepfather, Shane, had come to collect her. On arrival Shane told Alex about a difficult and complex situation at home involving Bridie's mother. Shane became more upset and agitated as he described the situation to Alex. Alex suggested that they move away from the public area and took Shane to the nurses' office to offer him some privacy and the opportunity to talk things through. After hearing about the situation and witnessing Shane's distress, Alex offered to extend Bridie's stay for another night. Shane was grateful for Alex's support and the opportunity for a little more time to resolve the situation at home.

### **Story Two**

Alex described a shift where she welcomed a family to the hospice and helped settle them in. The family consisted of the child Kayleigh, mum Sonia and Kayleigh's older sibling Trudy, who is a young adult. Sonia was a single parent and there was no contact with Dad. Sonia and Trudy planned to be resident during Kayleigh's short break at the hospice and had stayed many times before. Alex had known Sonia, Trudy and Kayleigh for five and a half years. Earlier in the day Sonia had phoned Alex to advise that they would be arriving at 3pm rather than 2.30pm. Based on Sonia's usual time keeping Alex estimated their time of arrival to be nearer 5pm. Ultimately they arrived at 3.30pm and when Alex greeted the family at the front door their first exchange involved some reciprocal banter about timekeeping. Alex noticed and commented that Sonia was looking less exhausted and brighter than she did on her last visit.

Whenever Sonia, Kayleigh and Trudy stayed at the hospice they brought a lot of personal items with them which made them feel at home. Alex described these as beautiful, soft, colour coordinated fabrics such as blankets, cushions and soft toys. Alex returned a blanket they had left behind on their last visit and this led to a conversation about a therapeutic crafting activity, i.e. felt-making, as a way for Sonia to relax and channel her feelings. The shift ended with a shared joke about Kayleigh being able to easily identify Alex due to her terrible singing voice.

Four themes were identified from Alex's stories:

- **It is their pain not mine**
- **Separating the work me and the home me**
- **Keeping it professional**
- **Counterbalances to emotional labour**



#### 4.2.1. It is their pain not mine

Whilst acknowledging the inevitability of feeling emotion at work, particularly in close relationships such as the one with Sonia, Alex believed that she could give 100% in her role as a nurse, offering empathy and compassion, without giving 100% of herself as a person. This seemed to convey the impression of holding something of herself back. Nevertheless, Alex did seem to acknowledge that nurses are reliant on the use of their own internal resources and personalities to forge interpersonal relationships so, although she may not give 100% of herself, she does give something.

As well as being important for her own mental health, Alex felt that the careful management of her emotions demonstrated professionalism. She spoke about times when she had witnessed excessive emotional displays and how inappropriate this was, especially if it resulted in a parent having to comfort a nurse. Her main strategy for emotion management was seeing the pain of the situation as belonging to the family and not to herself.

*So it's the family's situation. It's their, it's their pain and I just have to try and kind of separate that because, you know, you do see some really terrible things and situations and if you took them all on board you might crumble yourself, mighten you... I don't think it stops me being empathetic and compassionate.*

(Alex, telephone interview 2, p.4).

However, Alex did feel that limited displays of emotion such as her eyes glazing over when something moved her emotionally was helpful in showing parents she cared. Elements of Alex's account of emotion management are contradictory which is inevitable in complex human relationships. On one hand she talks about separation, on the other about the inevitability of involvement. My interpretation of what Alex is verbalising here are different dimensions of empathy. However, Alex's description of what she sees as inappropriate emotional displays in others would suggest an awareness of the potentially detrimental consequences of becoming consumed by empathy. Alex's articulation of being mindful to place the emotions of the situation where they belong, i.e. with the parents, whilst allowing herself a degree of emotional involvement appears to be a successful strategy for

managing emotional labour. Moreover, it suggests that Alex's degree of emotional involvement is within the realms of a therapeutic relationship, i.e. neither overly nor underly involved.

#### **4.2.2. Separating the 'work me' from the 'home me'**

In addition to peer support and daily informal debriefs, Alex mentioned some specific actions which she found helpful in getting closure on the working day and separating work from home. Firstly, the ritual of all staff leaving the shift and walking to the car park together, which she perceived as peer to peer support and signified the end of the working day. My thoughts on this are that the action of leaving the shift 'en masse' does suggest a feeling of solidarity and that there is no unfinished business from the shift. This could be a way of drawing a line under situations which are inevitably unfinished but are at least physically handed over to another nurse. Secondly, in terms of mentally ending the working day, Alex spoke about using the time between leaving work and arriving home to make the transition between her professional and personal identity.

*Driving home, you know just that, turn the music up and then just make sure you're.... I think it's that, it's just that little bit, period of time isn't it. It takes me about 25 minutes to half an hour to get from work to home, so by the time I've done that I've kind of let go ... then that bit of time just to think of nothing really and then just come home and you're back to (being) mum and wife and, and Alex in the house... You're getting on with family life as well at home and doing your own social things; that's important. (Alex, telephone interview 1, p.4)*

These strategies seemed to combine both physical and temporal endings to the working day, transitioning to home and re-establishing herself in her domestic role. The time taken to travel home from work appeared to be particularly helpful in assisting Alex to switch mind sets. Perhaps because she was engaging in activities which allowed her to both reflect on and distract herself from work, i.e. driving and listening to music. I would also suggest that this temporal separation from work could be a conscious effort to avoid excessive thought about families which may lead to overinvolvement.

#### 4.2.3. Keeping it professional

Alex mentioned that her own experience gave her an insight into the distress of the parents she worked with but had no wish, nor would it be appropriate, to share this with Shane or Sonia. For less emotive commonalities she felt that a superficial level of self-disclosure was an acceptable way of making a connection with parents. Her level of disclosure would depend on the length and nature of her relationship with the parent. So perhaps she would share more personal information with long-term parents with whom she had a 'close' relationship, such as Sonia. However, this is my supposition; Alex did not articulate this. An aspect of self-disclosure behaviour which was very clear in Alex's account was social media use and how information could be intentionally or unintentionally divulged via this medium. She was aware that some of her colleagues interacted with parents on Facebook but was diligent about avoiding any possibility of this, describing herself as 'boundaried'. However, she sometimes felt pressured to engage in similar behaviour and, since she did not join those who were befriending parents on social media, she worried that families may see her as less warm or slightly odd<sup>3</sup>. This was possibly a reflection of contemporary society and the propensity for sharing personal information on social media. This could lead to personal difficulties and could have serious consequences when relationships are supposed to be professional and, by their definition, confined to therapeutic interactions.

*I'm only new to Facebook, but I umm u, you know, I don't actually 'Like', I haven't 'Liked' the X (names hospice) website page because I don't want families being able to click, click on my, do you know what I mean? Find out about me umm and I think sometimes I see people have commented and that's been brought up in like a team meeting about being appropriate or inappropriate ... you can feel a little bit, if someone else is very sharing you can get that feeling of actually. Am I as good a, not as good a nurse but do I, do I (pauses) um touch them, in a, do you know what I mean? Do I get in to their, do they view me as a similar sort of nurse or do they view me as a bit odd because I don't do that. (Alex, telephone interview 1, p.18-19)*

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<sup>3</sup> Extract from reflective diary 10.3.19: I was dismayed to hear Alex say that she felt pressured to share personal information on social media and that she feared that not engaging in this behaviour may make her seem less 'warm' than others. Social media can be so artificial. I find it sad that there is any suggestion that she is somehow lacking in nursing attributes because she does not engage with families through it.

Of course, being someone's 'friend' on Facebook is an artificial notion as this can occur in a wholly superficial way which belies the real concept of friendship. Similarly, Alex highlighted the difference between being a friendly professional and a friend, referring to the potential for parents like Sonia to see her as a friend since she engaged with them in a homely environment where many social interactions took place. Alex noted that nursing staff not wearing uniforms was another factor which could lead to blurring of nurse-parent boundaries. Whilst she felt this was useful in perpetuating an informal atmosphere and relaxing families, it also meant that there was no clear visual delineation between staff and parents. She also felt that the trust placed in her by parents who were essentially 'handing over' the care of their child who had very complex care needs, might give rise to a closer relationship than elsewhere. Interestingly she referred to this as a 'bond' between herself and the parents, so there is a suggestion that this closeness may be somewhat reciprocal. However, Alex was keen to clarify the boundary between being involved in a parent's life as part of your work and being involved in their life on a social level.

*I think it's about your boundaries really. You've got, for me, I give 100% when I'm at work but I am very much there as the nurse, I'm not your friend, I'm not. I'm a friendly professional but I'm not your friend.*  
(Alex, telephone interview 2, p. 4).

Alex used an interesting analogy to describe how she keeps connected but separate from families, referring to keeping a 'bridge' between them. I would interpret this as connection but from a distance with the metaphorical river, road or rail track running beneath the bridge as the boundary or line between her and the family.

Both Alex's approach to self-disclosure and views on the nature of her relationship with parents suggest that she is fully cognisant of the potential pitfalls of sharing too much personal information and has a clear idea of the confines of the therapeutic relationship.

#### 4.2.4. Counterbalances to emotional labour

Alex outlined many positive things about the job and the environment which reduced her stress and improved her mental health. She described immense job satisfaction, despite the emotional labour of the work and even referred to the notion that it is a bit strange to gain satisfaction and enjoyment from looking after dying children. She spoke about the moments of joy and 'magic' (in the sense of something special rather than miraculous) and the positive impact that being involved in memory making can have on the nurse as well as the family and child.

*I think that little things like that's kind of magic isn't it. Like sometimes you think gosh those couple of minutes are really magic and how many people get that from their jobs? I think that's quite lucky. ... So you've provided the child and the family with a memory but actually you've also done something that impacts on your own life in a lot of ways ..., that memory it sorts of sticks in your head as well.*

(Alex, telephone interview 2, p.8.)

Alex stated that this type of job satisfaction was something that helped counterbalance the demands of the role. However, I would suggest that this is not solely confined to job satisfaction. In the case of short break care in CHs, clinical nursing care is present and essential, but it is primarily in the 'background', i.e. a normal part of the child's daily life. So, in CHs the 'work' is weighted to activities which are often minimal or would be seen as frivolous elsewhere, e.g. spending time having fun with families and children. Thus, interactions are less task focused and more personal which enables the development of a nurse-parent/child relationship. This also offers the nurse something different to other care settings.

Alex further illustrated the positivity of CH care by referring to a poem 'Welcome to Holland' which she used to help parents navigate a parenting journey that they had not expected and to positively influence her own state of mind. Alex's outline of it is shown below and the full version appears in Appendix 12:

*...that poem you know that poem about you think you're going to Paris but you end up in Holland... I tell the parents ... when you're pregnant you imagine ...everyone tells you that you're going to Paris and you build up this plan of what Paris is going to be like and all the things*

*you've got planned to visit and do in Paris and then all of a sudden your plane ride is over and you land in Holland and you have to get used to the fact that you've come to somewhere that you didn't anticipate ... you want to be in Paris but then actually, as time goes on, you realise that Holland's quite a beautiful place it's got tulips, it's got things that you didn't quite anticipate and you can find some beauty in that.* (Alex, telephone interview 1, p.6-7)

Alex's description of the poem suggests the possibility of personal growth in parents of children with life-limiting conditions and the nurses who care for them, i.e. the positivity and fulfilment that can be found in caring for a child with a life-limiting condition.<sup>4</sup> During my analysis I did ruminate about the significance of Alex using something aimed at helping parents to positively influence her own state of mind. I wondered if this linked with the death of her sibling, but the essence of the poem is living a different life rather than living life to the full. I also pondered on the notion that perhaps the underpinning CH philosophy of positivity and living life to the full is so ingrained in Alex that she has started to adopt the same tools to care for her own well-being. Particularly as she also referred to the crafting activity of felt-making in such powerful terms as constructing a whole from pieces (perhaps a metaphor for rebuilding oneself).

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<sup>4</sup> Extract from reflective diary 10.3.19: Alex would need to use careful judgement of timing and parental state of mind to use this – discussion of this would be outside the aims of the thesis as in this instance she is using it to illustrate how she frames her own positivity. Post-script note 17.3.19: Searched for this poem on the internet. It is, in fact, a short essay and the destination in the original was Italy not Paris. Further post-script note 24.7.20.: My thoughts about careful management and sensitive use of 'Welcome to Holland' were confirmed by the content of a blog '*The Trouble with Welcome to Holland*' where parents state that though well-meaning, the essay is often used insensitively and is either loved or despised depending on parental state of mind on that particular day.

### 4.3. Chris

Chris became a registered children's nurse upon qualification 19 years before participating in my study. At this time she had worked at the hospice for six years. Her previous experience was in general medicine, adolescents, surgery and oncology. She was in her early 40s. Chris' story is outlined in Box 4.2.

#### **BOX 4.2: CHRIS' STORY**

Chris told the story of a challenging conversation with a mother she had known for over six years. Single parent, Sarah, was struggling to tell her 16 year old son, Charles, the truth about his current prognosis and whether it would be possible for him to be discharged from the hospice. Charles had mild learning difficulties but was able to understand what was said to him and what is happening around him. He was known to suffer from bouts of extreme anxiety. He had a degenerative condition and was confined to bed due to his underlying condition and secondary health issues. His symptoms were being managed at the hospice and efforts were being made to organise service provision for home care. He was very keen to go home but due to difficulties managing his symptoms and problems with securing home care provision this was unlikely to happen in the short term. His underlying condition was also deteriorating and it was likely that he would not survive beyond the next six months. Charles continually questioned Sarah, the nurses and doctors about when he would be going home and how long he had left to live. Sarah deflected Charles' questions by offering platitudes. Chris stated that essentially Sarah was lying to Charles but went along with it, sometimes verbalising the same platitudes as Sarah.

Four themes were identified from Chris' story:

- **Self-care strategies**
- **Only my peers really understand**
- **Balancing personability and professionalism**
- **Competing priorities**

#### **4.3.1. Self-care strategies**

Although Chris was sometimes affected by the emotional labour of her work, including having dark thoughts about the health of her own children, she felt that for the majority of the time she was able to successfully manage this with

well-developed self-care strategies. One of these was ensuring her social circle did not involve nursing colleagues as she felt that conversations would inevitably entail work. This struck me as unusual because many of my own friends are past or current work colleagues. Chris did seem to have a strong friendship group and did not express any regret that the conscious decision to limit this to non-nurses would mean missed opportunities for friendships. She described how she kept 'sane' by enjoying time with her family and socialising with her friends. Chris also described other self-care activities which helped her switch off from work and keep emotionally well:

*I like to meditate and relax with candles or have a massive blow out with my friends every now and then. So I've got a separate life to nursing and that's really good for my mental health I suppose, because it keeps me grounded.* (Chris, telephone interview, p.2).

Essentially what Chris is describing here are behaviours which are almost opposite. On the one hand she occasionally lets off steam by having what she describes as a 'blow out' with her friends and on the other hand she indulges in very quiet, peaceful activities. From Chris' description of her self-care activities, it was clear that the quieter activities were a regular occurrence whilst the social 'blow out' was occasional. I wondered if the 'blow out' (as the phrase suggests) became necessary when tensions had built up and could no longer be alleviated by regular, gradual release. This made me think of a pressure cooker where the regulator was opened a small amount periodically but when the pressure built up to an unmanageable level the valve had to be released completely.

#### **4.3.2. Only my peers really understand**

For Chris the main counterbalances to the emotional demands of the role were peer support and working as a team. Although there were other support mechanisms such as provision of a clinical psychologist, clinical supervision and regular debriefs, peer support was the most important because she felt that only her peers could really understand the nature and demands of the work, whereas even someone as close to her as her husband could not.



*I believe that it's really only your peers who understand... they are the only ones who understand the situation, what it is. So no one else does other than my peers in work really. I could come home and explain a situation to my husband and he literally switches off (laughs). Got no idea at all about the reality of working in a children's hospice and no one has. (Chris, telephone interview, p.7).*

She often highlighted the role of the team when describing the situation with Sarah and Charles and had worked closely with a colleague to try to find a resolution. Chris talked about how safe she felt in discussing her feelings with her peers even when they held differing viewpoints about an issue.

Peer support is important in any situation but from her narrative I gained a sense of something deeper than one would normally expect, i.e. really understanding the reality of working with parents whose child is expected to die before reaching adulthood against the 'backdrop' of a happy place where the focus is making memories and having fun. Unsurprisingly, the contradiction and real nature of hospice is difficult to explain to others even, it seems, to one's spouse. The relationship between peers that Chris described to me made me think of a tight knit community who, due to their unique shared experience, are the only ones who have a real insight into it.<sup>5</sup> Of course the lived experience is different for all, so there is always an element of different feelings, viewpoints and interpretations, but there is a distinct difference between those who have experienced something and those who have not. However, I also wondered if Chris' description of her husband switching off when she tries to explain a situation is more about a natural aversion or unwillingness to hear and therefore think about the nature of her work per se.

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<sup>5</sup> Extract from reflective diary 1.8.20: Thinking about this analogy brought to mind the Aberfan disaster – A small community who experienced a tragic event. The experience of the death of their child was common to many villagers but none would feel the same or grieve in the same way. However, they were united by the experience and supported each other (they still do more than 50 years later). People throughout Wales (indeed throughout the world) were stunned and upset by what happened in Aberfan but could not even begin to imagine how it felt to be one of those parents.

### 4.3.3. Balancing personability and professionalism

Chris was under the impression that many parents view her as a friend which, she felt, was a major challenge to maintaining professional boundaries. She suspected this occurred because their lives were dominated by healthcare professionals, so most of their adult-to-adult interactions took place during care delivery. Chris was clear that the notion of friendship was not a mutual one. Although she identified some of her long-term relationships with parents as 'close' she was able to differentiate this from the type of connection she would have with someone she was close to outside of work.

*... this perception that we're their friend but it's not a mutual thing. Because their world is professionals and no one else really. Some of the children with complex needs, all they've got is professional people and I think that their perception is that we are their friend... I don't view them as my friends at all. So therefore, it I wouldn't be on the same level as a real friend. (Chris, telephone interview, p3).*

This is, I would suggest, Chris' impression of the parents' perception. It is not possible to ascertain from this study if this is truly what parents think about hospice nurses. However, it is natural for a person to become 'friendly' with any person they see on a regular basis, if the environment is conducive to having some sort of dialogue. For example, you might become 'friendly' with someone in the local newsagents who serves you regularly but you would be unlikely to tell someone else that they were your friend. Perhaps parents who are trusting nurses to look after their child with highly complex care needs may see the relationship differently because they need to feel that the nurse is personally invested in their child. Alternatively, perhaps getting to know nurses over a long period of time could lead to the perception of friendship, particularly if the nurse discloses any personal information. Given that Chris was happy to divulge quite a lot of superficial personal information with families (discussed below) this may have contributed to families seeing her as a friend (if indeed this was the case). Ultimately this depends on the individuals' definition of 'friendship' and whether this includes lots of superficial relationships or is confined to a few close ones. I would suggest that if there is a 'risk' of parents seeing nurses as friends, the factors that might contribute to this are primarily under the control of the nurse, i.e. clear

articulation of their role both externally and internally and limiting personal disclosure.

Whilst acknowledging that some colleagues would be reluctant to divulge any personal information Chris was happy to do so. In fact, she would feel awkward declining to answer a personal question since she felt it was her role was to keep the conversation flowing and make the family feel welcome. Initially I had the sense that she was saying that she felt obliged to share personal information to avoid spoiling the cordial atmosphere of the hospice. However, on further exploration it was clear that the felt obligation was to maintain the pleasant atmosphere rather than to reveal information she was not happy to share. Nevertheless, the superficial information, or 'small talk', as she labelled it, included the facts that she was married and had children. My observation is that this is essentially dependent on how an individual defines small talk; some would share Chris' view that the things she is happy to share amount to superficial, inconsequential information, others would not.

*No, but I wouldn't say 'I'm not going to answer that' either. I would just try and find the right words to make a pleasant conversation and not, not have difficulties ... I would just rather have pleasantries all the time. Yeah. Make a nice atmosphere and make them feel welcome really. So yeah, I'm quite good at small talk, that's what I consider it as (laughs). (Chris, telephone interview, p.3).*

I would suggest that the obligation to maintain a pleasant atmosphere is a general feature of service provision, so not specific to the hospice. However, the CH model and the reason for its existence may accentuate this. Moreover, in everyday life, during transactional or brief interactions, 'small talk' is usually used to describe conversations which are confined to benign, unimportant topics such as the weather but it would be difficult to sustain a conversation on this level for any length of time. So, it may be possible that the 1:1 nature of hospice work and lengthy relationships means that trivial, neutral topics are soon exhausted. This may have led Chris to redefine her definition of 'small talk' to a level of personal information which would be of little consequence, e.g. being married (many are), having children (many do). Alternatively, it could be argued that 'small talk' in professional caring relationships should be more limited than in everyday life since divulging

personal information to a stranger during a solitary encounter is much less likely to cause difficulties than revealing personal information to a client who you will see repeatedly, because this may lead to curiosity and further questioning.

#### 4.3.4. Competing priorities

Chris' story highlighted the challenges of balancing her long-term relationship with Sarah versus her duty to Charles. She felt that long-term relationships with parents facilitated mutual trust and honesty. However, she remained challenged by honest conversations with parents, particularly when they were highly assertive. She found that this was often the case with those who had to continually fight for service provision, navigating complex health and social care systems. She may have highlighted this to show why it is sometimes difficult to set aside parental wishes, but she did not explicitly apply this to Sarah.

Chris was left feeling very uncomfortable about the situation because whilst appreciating the reasons for Sarah's reluctance to tell Charles the truth (his history of severe anxiety), she felt that withholding the facts was not in his best interests and was, in essence, lying. Nevertheless, further discussion revealed that if Charles had questioned Chris directly, she would respond in a similar way to Sarah <sup>6</sup>

*If you've got a parent that's very adamant that they don't want you to be honest with their child at all then we would respect it, even if our personal feelings are that maybe that's not the right thing... I would try to change the subject (nervous laughter) because I know that mum really didn't want him to know ... So I, we went along with it really... I did struggle with it actually a lot. (Chris, telephone interview, p.1-2).*

This dilemma appears to illustrate the difficulties of operationalising the hospice philosophy of caring for the whole family equally. Whilst a nurse's

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<sup>6</sup> Extract from reflective diary 18.12.19: I really feel for Chris in this dilemma. I have experienced similar situations in an oncology setting. I did find myself thinking that she really should tell Charles the truth, that that was the right thing to do. Though I am conscious that I'm making a judgement here – this is not black and white, it's complex and there is no easy resolution. In all honesty I would probably do the same as Chris and hope that with time and effort I could support the parent to tell the truth.

focus is the child and other CH staff are specialists dedicated to providing parental support, the length of time nurses spend alongside children and their families during the course of a shift, is likely to lead to instances where this duality of the nurse's role arises. I wondered if the conflict felt by Chris may have implications for her mental well-being, especially if the situation remained unresolved.

#### **4.4. Les**

Les had been a registered children's nurse for 18 years. She was also a registered health visitor. She had worked at the hospice for four and a half years. Her previous experience was in children's oncology, neurosurgery and medicine. She was in her early 40s. Les' story is outlined in Box 4.3.

##### **BOX 4.3: LES' STORY**

Les told the story of her interaction with Verity (Mum) and Mitch, a child aged 9 with a genetic, multi-system disorder, inherited from his mother. Les spent time with Verity and Mitch, admitting him for short break care. Verity would not be resident as she and her partner (Mitch's dad) were using this short break care stay as an opportunity to spend time with their other child. Les had known the family for four and a half years, i.e. the whole time she had worked at the hospice. The admission, which took an hour and a half, was straightforward. Mitch visited the hospice for short break care approximately twice a month as he had been identified as a child in need. This was due to his parents not always recognising his care needs in a timely way. Les stated that this was not a punitive thing and that the parents appreciated the extra support because they realised that they sometimes struggled to meet his medical and fundamental care needs. Les described Verity as amiable and chatty. She felt that they had a good relationship.

Three themes were identified from Les' story:

- **Keeping families at 'arms-length'**
- **Zero self-disclosure: avoiding the slippery slope**
- **Buttoned up or burnt out?**

#### **4.4.1. Keeping families at 'arms-length'**

Les adopted what she referred to as a professional, 'arms-length' approach to her relationships with parents. She was clear that her role was to nurse the child and avoided becoming embroiled in conversations about the parents' feelings; referring them to the hospice well-being team when they needed emotional support. She identified this as both a self-protective measure and because she felt she did not have the necessary counselling skills to help parents. Les was unique, inasmuch as, in contrast to other participants, she did not feel her relationships with parents at the hospice were any different to those she had in the hospital setting, despite the contrasting environment and model of care delivery. Les felt that the hospice philosophy was similar to that of hospital wards; suggesting that either the type of wards she had worked on (oncology and haematology) did have similar philosophies of care, i.e. that fully encompassed the parents or that she viewed the care of the parents as the role of others. I would suggest that the latter may be the case due to her described propensity to refer parents straight to the well-being team in times of distress. Alternatively, it could be argued that perhaps Les is just realistic about her skills and more definite about her role than the other participants. Nevertheless, the term 'arms-length', to describe her relationship with parents, conjures up an image of keeping them away, in a somewhat defensive manner, rather than supporting them from a professional distance.

Les acknowledged that her approach to managing her relationships with parents was different to that of her colleagues since, at times, they became very emotional and openly displayed this at work. She conceded that she was not completely unaffected and was keen to stress that her 'arms-length' approach was a positive. This was because the milder personal emotional impact she experienced enabled her to support her colleagues both practically and emotionally when they were struggling to function. However,

when articulating her approach Les became concerned that this made her appear unfeeling<sup>7</sup>.

*I think because possibly you know the slightly more arms- length that I keep than other people do. I don't get affected as much. I can think of an example recently... it does bring home the emotions and how involved people are but again I, I felt that I was more useful kind of being there as support for them. I didn't get (trails off), I do sound incredibly cold don't I! (Les, telephone interview, p.5)*

It could be suggested that Les' description of managing her relationships with families indicates that she may be somewhat detached from the therapeutic relationship, possibly due to repeated exposure to emotional labour through this and her previous roles.

#### **4.4.2. Zero self-disclosure: avoiding the slippery slope**

Les described a very clear, rigid approach to self-disclosure and would never reveal any personal information to a parent, even the most innocuous commonality; depersonalising these by referring to 'a friend'. She saw this as professionalism but also highlighted that she was a very private person. Personal questions posed by parents were deflected in a light-hearted manner whilst stressing that she was there to nurse the child, not to talk about herself. Les felt that her 'black and white' approach to non-disclosure was a way of avoiding the '*slippery slope*' of revealing too much and subsequently not being able to return to a more professional footing. She referred to these instances of misjudged self-disclosure as 'horror stories', perhaps indicating a reason she had adopted this approach. She also acknowledged that unlike her colleagues she did not have children, so could not be drawn into this type of conversation.

Despite her apparent confidence in her approach Les did express anxiety that she appeared 'cold' or 'anti-social' and stated, '*I've realised that my*

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<sup>7</sup> Extract from reflective diary 7.11.19: Les' comment about appearing cold is really interesting. The way she approaches her relationships with families has clearly been developed over time, she is happy with it and it works for her. However, actually stating it out loud made her question herself – not whether the approach was the right one but she seemed worried about how it made her appear as a human being and as a nurse.

*privacy settings are kind of crazy'* (Telephone interview, p.8).<sup>8</sup> She was keen to stress that she was a good nurse who was friendly and chatty but who carefully managed conversations by keeping them to the present rather than the past or the future, where personal matters may arise. Despite already offering a number of explanations for her approach, it was interesting that Les felt it necessary to stress that she was a good nurse, which I thought might be because the persona she was presenting was somewhat contrary to the PR image of hospice nurses, i.e. open, sociable, loving individuals.

*I'm not a ridiculously anti-social person that I might be coming across as but, ... keeping it vague and in the moment rather than history and future plans and whatever. Yes, I just manage to chat around stuff and if there's something that I think ... I can have a bit of a chat about that... I tend to use a 'my friend' or something like that, rather than me personally.* (Les, telephone interview, p.2)

Les' reserve extended to her colleagues, deliberately concealing some very happy news during a recent study day. Nevertheless, she was happy to tell me, a virtual stranger - an anomaly she swiftly acknowledged<sup>9</sup>. Perhaps, despite her professional experience, Les lacked the confidence or ability to be flexible, as her approach did seem extremely rigid particularly for a nurse. This suggests a straight, bold line that could never be crossed, whereas other participants seemed to have a line which was somewhat moveable to accommodate differences in their relationships with individual families.

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<sup>8</sup> Extract from reflective diary 6.11.19: In addition to worrying about appearing 'cold' it was interesting to hear that Les worried about appearing anti-social too, particularly in light of the social nature of hospices referred to by other participants. Les' reference to 'privacy settings' is congruent with social media terminology – she didn't mention social media so perhaps this is just a reflection of contemporary society or maybe a useful analogy that Les applies to her working life.

<sup>9</sup> Extract from reflective diary 6.11.19: I was really struck by how similar Les' approach to professional boundaries was to the one I had started my doctoral journey with. This was because I was aware of my potential to cross boundaries by offering extra help (particularly in health visiting). Listening to Les made me wonder whether in the past she had given herself a bit of a fright in terms of overstepping a boundary (as I had) and so subsequently adopted this very strict stance to self-disclosure. This was a general feeling but also the fact that she was very happy to spontaneously divulge some information to me that she was not happy to tell her colleagues. Perhaps the distance provided by the telephone also enabled this. There is also the possibility that she was providing what she thought to be the 'right' responses to my questions. I doubt it though as, apart from her spontaneous disclosure to me, she was consistent in her responses about nurse-parent relationships.



#### 4.4.3. Buttoned up or burnt out?

Although Les acknowledged that she was less affected by the emotional demands of the role than others she did recognise the need for some emotional support; the primary source being formal mechanisms.

*...you just kind of find your way ... we do have the debriefings and ... we do get supervised quite a lot, clinical supervision, management supervision.... happens quite a lot and I think that nips things in the bud before you know, without you really realising ...*

(Les, telephone interview, p.5)

Les was the only participant who did not mention peer support which I found surprising, given that it is such a significant coping mechanism for the others. Her approach to all aspects of her role gave me a sense of someone who was very self-contained and her preference for formal rather than informal support mechanisms may suggest that she avoided revealing vulnerabilities to those she works alongside, particularly as she even avoided sharing happy personal news with her peers. However, she did refer to talking with her very small group of close friends (mostly nurses but not current colleagues) about things that bothered her at work. So, the extreme self-restraint Les exhibited at work did not appear to wholly apply to her life outside work. I would label this as a very 'buttoned up' approach to dealing with the emotional aspects of the role, indeed stating that she was not hugely affected by it, together with her apparent lack of engagement in peer support suggest that Les is somewhat detached from her work. Examining this alongside Les' concerns about appearing cold, which suggests she had insight into the unusualness of her approach, I wondered if Les may be burnt out or suffering compassion fatigue.

#### 4.5. Jo

Jo had been a registered children's nurse for 15 years. This was her only NMC registration. Her previous experience was in general CYP nursing and a special care baby unit. Jo had worked at the hospice for 12 years and was the youngest participant, being in her late 30s. Jo's story is outlined in Box 4.4.

#### **BOX 4.4: JO's STORY**

Jo's story was about a family she had known for 10 years. The young man Jo cared for was named Andy who was aged 13. He lived with his mum Hayley and his dad John. Jo spoke to me about an occasion when Andy came to the hospice for day care. The day care provision was slightly unusual in that on this particular day Andy attended the hospice with his best friend. The ethos underpinning this was that when Andy, who had a liver and bowel condition, needed end of life care his friend will be familiar with the hospice and feel comfortable visiting Andy there. Jo's interaction with Hayley was by email and telephone in the weeks prior to the stay, during the time Andy and his friend were dropped off, on the telephone an hour before Andy was collected and during the time that Hayley collected Andy. The reason for the telephone conversation near to the end of Andy's stay was a problem with a technical aspect of Andy's care. Jo was dealing with this but she wanted to keep Hayley informed since the issue would require further exploration after Andy left the hospice. Jo described her relationship with Hayley as very good but she was aware that she did have a tendency to be rather forthright in her communications with other professionals.

Three themes were identified from Jo's story:

- **Emotional barriers and self-control**
- **Intrinsic counterweights to emotional labour**
- **Self-disclosure: a difficult balance**

##### **4.5.1. Emotional barriers and self-control**

Jo spoke about how nurse-parent relationships at the hospice had 'another dimension', when compared to ward areas. She identified this other dimension as more personal, yet still professional. She attributed this to the homely environment, which is geared to informal, social interactions and having time to spend talking 1:1 with families. Jo maintained a professional approach and attitude by making a clear distinction between being involved in a family's life for work, i.e. her job, and being involved with a family on a personal level. Further she spoke about firmly switching her mind from work to home at the end of the working day.

Nevertheless, she acknowledged the potential for CH nursing to provoke personal emotional responses, particularly with long-term families. She managed this by placing a conscious emotional barrier between herself and families. An approach she clearly identified as professionalism whilst taking care not to negate the sadness of the situation. This gave me the impression that Jo was trying to stress that effective emotion management did not equate to being unfeeling.

*So I think, I think you just have to be, you've just got to remember that this is, although I need to be compassionate and I need to be involved in this families life I am not actually involved in this life ... you're not upset in the same way that you'd be upset if it was someone that you've loved as a family or friend. (Jo, telephone interview, p.7)*

*I think you just have to, to work in a hospice you just have to be able to have that barrier, and that professionalism, that it's sad but it's your job and that's what you're doing. (Jo, telephone interview, p.8)*

It seems that what Jo is referring to are elements of self-awareness and different dimensions or levels of empathy. Particularly as she highlighted the lack of professionalism demonstrated by some colleagues who had become so emotionally involved with families that they were unable to avoid public displays of emotion, such as uncontrollable sobbing. This suggests that Jo deems self-regulation to be an important element of professionalism.

#### **4.5.2. Intrinsic counterweights to emotional labour**

Job satisfaction was a major positive in Jo's working life and this helped to counterbalance its emotional demands. She spoke about gaining satisfaction from being able to deliver such high quality, bespoke care, having time to spend with families and supporting them through awful times. As well as gaining immense satisfaction from her job she also enjoyed it. She relished the variety, the making memory activities, the chance to give families opportunities they would not otherwise have, the focus of living well, the positivity of the approach and joyful atmosphere that prevailed for the majority of the time.

*I think it's hard to explain isn't it, as you would know, to people who have never worked or had anything to do with a children's hospice ...making memories and having fun ... I know when I first started working there I thought you would just be comforting parents when they were upset, all the time but actually ... you are not doing that all the time, you're just making those memories and having fun and doing as much as they can. But I think the balance is definitely, on a personal level, is good. (Jo, telephone interview, p.5)*

I would suggest that the elements of hospice work which are designed to give children and families a good experience, such as bespoke care delivery and promoting living whilst dying, result in a level of job satisfaction that goes beyond being a counterweight but actually outweighs the distressing elements of the role.

Another counterweight to emotional labour identified by Jo was peer and organisational support. A shared understanding of the uniqueness of the role enhanced peer to peer trust and peer support activities occurred regularly throughout the shift.

*I think as a team we are all really supportive of each other, we're all in the same boat... we do quite a lot of debriefing, kind of not an organised debrief but we do chat amongst ourselves and we support each other in that way, which I think is really good... getting us together at the end of the shift to make sure everybody's OK and just to make sure that people don't take anything home with them.*  
(Jo, telephone interview, p.11-12)

The availability of time was a factor which positively influenced peer support. Not only did Jo and her colleagues have the inclination to support each other because they understood the demands of the role, they also had the time to do so. Moreover, there was also time and capacity for formal debriefs, clinical supervision, talking to a spiritual advisor or well-being team and an opportunity to take 'time out' whenever it was needed. Typical 'time out' activities were mindful activities such as colouring or walking in the grounds.

Once again, I would suggest that the configuration of hospice services not only helps families but also benefits staff. So, 1:1 nurse:family ratios enable bespoke care which mirrors the care the child would need at home but this gives nurses more time to manage the emotional demands of the role for themselves and others. In terms of organisational support, one could argue it

is inevitable that staff well-being is well provided for in the hospice environment. However, the level and nature of peer support outlined by Jo would certainly seem to be extraordinary.

#### **4.5.3. Self-disclosure: a difficult balance**

Jo had a clear idea about what information she was and was not prepared to share with families. Essentially this was superficial information and small talk, but not detailed information. In common with Chris, Jo highlighted that the essence of the hospice is for a friendly, relaxed, pleasant environment where parents feel comfortable. So when she was asked personal questions that she was not prepared to answer it was difficult to deflect these without causing offence and she was careful to avoid being blunt.

*I wouldn't want to say, because of the environment that it is, I wouldn't like to say actually I'm not going to tell you about my private life but I would say 'I've got two daughters and yeah they are 7 & 8. So not necessarily use names ... I definitely wouldn't give them too many details. (Jo, telephone interview, p.4)*

*...I suppose you do have to have that skill of being able to just chat to them. I suppose make a bit of small talk really at a kind of appropriate level because you have some parents who come in and just I suppose you chat to them at a very basic level and then other families who just want to sit and chat. (Jo, telephone interview, p.9)*

Like Chris, Jo managed her conversations by offering personal information she saw as 'small talk' which included being married and having children but nothing further. So again, a definition of 'small talk' which goes beyond what some would deem acceptable but fairly innocuous, nonetheless. In contrast to other hospice features which assist staff, such as the availability of time for peer support, I would suggest that there seems to be a juxtaposition between delivering the expected ambience and maintaining professionalism. These two things are certainly not mutually exclusive but for those without a clear sense of boundaries, resisting the temptation to be drawn into more personal conversations could be problematic.

#### **4.6. Ashley**

Ashley was dual qualified (adult and child). She had been a registered children's nurse for 34 years and had worked at the hospice for 32 years. Her previous experience was in school nursing, general CYP nursing and children's oncology. In addition to working at the hospice she worked at the local special school which was attended by many of the children she cared for at the hospice. Ashley was one of the older participants, falling into the age bracket 51-60. Ashley's stories are outlined in Box 4.5.

## **BOX 4.5: ASHLEY'S STORIES**

### **Story One**

Ashley described caring for a family group who were visiting the hospice to discuss the care of a young man called Joe. Joe was currently resident at the hospice. (The situation is fairly unique so I will not describe it here due to the risk of breaching confidentiality.) It was a highly emotive discussion involving Joe's Mum (Sandra) and to a lesser extent his Dad (Mike). Ashley was acquainted with the family outside of work because her daughter had attended the same school as Joe's sister. In fact Sandra asked Ashley about her daughter's new job during the time they spent together. Ashley was happy to talk about this because she knew her daughter had shared it on social media. Joe's sister and her partner were also present. (Data analysis for the audio diary and telephone interview focused on Ashley's interactions with Sandra and Mike).

### **Story Two**

Ashley's second story was about a family she had known for three and a half years. She cared for the child at the hospice and at school. The family comprised Mum (Anne), Dad (Doug), the well sibling (Rory) and Max who has Mucopolysaccharidosis (MPS) disease. Max had been resident at the hospice whilst Anne, Doug and Rory went away for the weekend. Max was part of a clinical trial, aimed at slowing the progress of the disease. Some aspects of the treatment were working well but due to side effects it would be necessary to commence chemotherapy. Anne and Doug had decided against this. They planned to withdraw Max from the trial as he would not be able to understand why he was receiving chemotherapy. Furthermore, the hyperactivity associated with MPS would make administration of chemotherapy very difficult. The decision to withdraw from the trial, which Anne had advised Ashley of a few weeks prior to Max's stay at the hospice, would mean that there were no further options for slowing the progress of his condition. He would be likely to deteriorate fairly rapidly. Ashley's story focused on the end of Max's stay when Anne, Doug and Rory arrived to collect him. Max had had a good weekend, spending lots of time outdoors which helped manage his hyperactivity. Anne, Doug and Rory had really enjoyed their weekend away and were in good spirits when they arrived at the hospice. They had arranged to arrive at teatime so that the family could share a meal with staff before returning home. Just before the meal was ready to be served Ashley was helping Anne to collect Max's belongings together. Ashley asked Anne how the meeting at the hospital had gone. Ashley was referring to the meeting when Anne and Doug would be telling the clinical trial clinicians that they would not be continuing. However, Anne misunderstood and thought Ashley was referring to a pre-assessment for a general anaesthetic (should Max ever need one). This other meeting had resulted in a very positive outcome. When Anne realised that Ashley was referring to the meeting with the clinical trial staff (which was yet to take place) she became visibly upset. Almost immediately Ashley observed Anne's demeanour to be one of 'pulling herself together' and forced cheerfulness. So, on their subsequent encounters at the hospice and school, she was sensitive to the fragility of Anne's overly cheerful 'public face' (which she often observed in parents who were experiencing emotionally challenging times) and did not raise the subject of the clinical trial unless Anne did.

Three themes were identified from Ashley's stories:

- **Emotions: It's about them not us**
- **They think we're their friends**
- **Instinctive self-disclosure**

#### **4.6.1. Emotions: It's about them not us**

Ashley approached emotion management by putting her own feelings about the family's situation to one side to focus on supporting parents. This was verbalised in frequent references to 'accompanying' the family on their journey rather than living the experience and emotions for herself. She recognised that she was emotionally affected by the work but this was as an 'onlooker' rather than a central character. Ashley stressed that it was not about being unfeeling or erecting impermeable barriers. In fact, in intense situations, such as with Sandra and Mike, she spoke about absorbing their distress and working with them to identify what would be helpful and supportive.

Ashley acknowledged that she was attached to certain families and that this posed a challenge to emotion management. However, peer support, supportive management, reflection, self-awareness and pro-active self-preservation helped her recognise when this might cause an issue and take appropriate action, e.g. asking not to be allocated to a particular family during a short break stay.

Ashley's main objection to excessive emotional involvement was that it was likely to lead to extreme displays of upset, such as inconsolable sobbing. She viewed this as highly inappropriate and unprofessional, although she did feel that some indication that she was emotionally affected by a family's situation was acceptable (indeed appreciated by families) provided she could still function as a professional.

*... it's not for them to be supporting me with my upset and my emotion, it's about me being the professional and supporting them ...*  
(Ashley, telephone interview 1, p.1)



Ashley's description of emotion management and her professional persona, i.e. her 'professional face', being brave and strict management of her outward emotional behaviour, suggests high levels of self-regulation.

#### **4.6.2. They think we are their friends**

Ashley highlighted the possibility that parents could view hospice nurses as friends. This especially applied to those who were socially isolated and whose only interactions, outside their immediate family, were with health and social care professionals. She felt that this was further compounded by the 'homeliness' of the hospice environment, absence of uniforms, flexibility of care routines and the overarching social nature of interactions, e.g. dining together and social physical contact such as reciprocating a hug initiated by a parent. Ashley felt that these were all factors which made nurse-parent interactions less formal and more personal, hence making professional boundaries less defined than in hospital settings.

*... they have dedicated themselves to the care of these children; their only friends are other professionals and ... that that sort of family really, they really value those sort of interactions, which is fine because that's part of the job isn't it ... we do see it as part of our job, whereas you wouldn't be ringing up that mum a couple of weeks later asking 'are you free for coffee' whereas with one of your friends you would do. I suppose it is a slightly different footing.*

(Ashley, telephone interview 1, p.3)

It would appear that working in an environment which is designed to be a 'home from home' has the potential to alter the nurse-parent dynamic and whilst this appears positive for parents it does seem to pose a potential challenge to professional boundaries for Ashley. She highlights the delineation between friendliness and real friendship by citing the absence of planned social interactions outside of work. However, her referral to 'part of our job' would suggest that this was more complex than avoiding engagement in certain actions, rather it is indicative of a mindset which retains the professional role as the focus and resists the 'pull' of seeing social type interactions as anything other than work. This suggests Ashley used self-awareness, self-regulation and social skills to manage this aspect of her work. These are all elements of emotional intelligence, but it is also clear

that she is mindful of the professionalism required of her in her role as a nurse.

#### **4.6.3. Instinctive self-disclosure**

Ashley revealed that she was happy to divulge some personal information to parents because this helped them see her as an individual<sup>10</sup> but she did not clarify why this was an important factor in the relationship. She acknowledged that self-disclosure required careful management and was keen to emphasise that this would never include detailed personal information due to professional considerations and her personality. Decisions about whether to share personal information and at which level were based on instinct, how well she knew the parent, whether they were the type of person she would be friends with outside work and if she trusted them to keep the information private.

*... instinct is just the most important thing really...with families you've known a long time the professional boundaries can move slightly ... you know, there are some families that would respect the trust you have in them and would respect any information that they had and others would just use it as kind of gossip ...you have to be really careful about what you do, because ... actually you are, you know, professionals. (Ashley, audio diary 1, p.3)*

It was interesting to hear Ashley talk about what is essentially gut instinct in respect of relational rather than clinical nursing, which is often debated but usually attributed to a deeply grounded tacit knowledge base which enables identification of minute signs and symptoms. Relying on gut instinct to guide personal disclosure did seem a little at odds with her reference to professional behaviour, particularly as misjudgement of whether a parent could be relied upon to keep information private would be likely to pose more of a risk than a similar misjudgement outside the workplace. However, it could also be argued that a nurse of Ashley's experience, particularly within

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<sup>10</sup> Extract from reflective diary 31.8.19: It struck me afterwards that perhaps it was important for parents to see Ashley as an individual because of the more personal social nature of the relationship. Otherwise why would it be important? Then I wondered- important to who? Was this really what parents want – some of the literature I had read suggested that it was. Or was it more about the personal needs of Ashley to be seen as an individual and not just 'the nurse'.

CH nursing, may have developed a high level of instinct in relational aspects of nursing. So perhaps her instinct is rooted in a well-developed knowledge of human behaviour which enables her to make measured, reliable judgements about the parents she works with.

#### **4.7. Patrick**

Patrick, the only male participant, was the last to be recruited and like Ashley fell into the age bracket 51-60. Patrick had been a registered children's nurse for 26 years and was also a Registered General Nurse. He had worked at the hospice for five years. His previous experience was in high dependency, oncology, general/respiratory, community, homebased respite and special care baby unit. Patrick's stories are outlined in Box 4.6.

## **BOX 4.6: PATRICK'S STORIES**

### **Story One**

Patrick's first story was about his interaction and relationship with the family of Bryan, a five year old child with a rare genetic neurological condition. The family consisted of Bryan's mum Judith, his half-sister Evie and his grandmother, referred to as 'Nanny'. Patrick had known the family for approximately four years. Patrick described Judith as amenable but reserved and on occasions difficult to engage in conversation. Therefore it was sometimes difficult to obtain information from her. Patrick had to work quite hard at this, either dropping hints when he had basic information about an issue and needed more or asking very direct questions. Patrick had a more convivial relationship with Nanny, who was closer to his age than Judith. Patrick usually obtained most information about the family's situation from Nanny. Interactions with the family usually started with what Patrick described as 'banter' with Nanny and Evie. Judith was usually slightly on the periphery of this but once she relaxed she was happy to join in. Patrick felt comfortable and relaxed with the family.

### **Story Two**

Patrick's second story related to Carl who was 7 and his family, comprising his mum Joan, his step-dad Harry, his half-sister Maddy and his step-brother Simon. Carl had cerebral palsy, following a traumatic birth. He had a number of cognitive and physical difficulties which meant that he was considered to be 'life-limited' and unlikely to survive into adulthood. Patrick was the key worker for the family and had known them for 6 years. On this occasion he was admitting Carl to the hospice for short break care. Joan was dropping Carl off for his stay and was keen to leave. She, Harry and Maddy had plans for the weekend. Patrick spoke about this interaction but also about his relationship with Joan more generally. Patrick described Joan as rather 'black and white' in her approach to Carl's care and that she was reluctant to review decisions about Carl's advance care plan. Due to past misunderstandings Patrick felt that Joan was wary of professionals and that she often perceived suggestions as criticism.

Three themes were identified from Patrick's stories:

- **Strategies for managing emotional involvement**
- **Being friendly but not being friends**
- **Purposeful self-disclosure**

#### **4.7.1. Strategies for managing emotional involvement**

Patrick was mindful that becoming overinvolved with families was not helpful to either party and that he should keep a professional emotional distance. His strategies for managing emotional involvement and subsequently

protecting his own well-being were rooted in how he viewed his role. He highlighted that he worked in a speciality where the end point is inevitably distressing but this is counteracted by the satisfaction of knowing the child and family's lives had been enhanced by the high quality clinical, social and emotional care delivered at the hospice<sup>11</sup>.

*With long-term disability, long-term illness, the children are going to live with it until either they're old enough that they turn into adults or they don't make it to adulthood. In the intervening time the quality of care, the opportunity to help the family to the best of your abilities... then that is a good thing. (Patrick, telephone interview 1, p. 15).*

Furthermore when a family's experience had parallels with his own life, such as making EoL plans with his parents, Patrick focused on using this as a means to understand how the family might be feeling rather than assuming congruency, reliving the emotions of his own experience or dwelling on how he was feeling about the family's situation. Patrick's articulation of the clear, careful but very subtle difference between how the family might be feeling about their situation and how he had felt in similar situations suggested high levels of self-awareness and self-regulation. In addition he empathised and could relate to their situation but kept the focus on the family so he could support them.

#### **4.7.2. Being friendly but not being friends**

Patrick spoke about how he enjoyed building trusting relationships with parents and that hospice work gave him the opportunity to do this, since the duration was usually longer, the work less task focused and more about supporting the family as a whole; all of which he identified as putting the relationship on a different footing. He felt that to some extent nurses inevitably became part of the family and there was danger of professional

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<sup>11</sup> Extract from reflective diary 6.11.19: Interestingly Patrick didn't mention being personally affected by the emotional demands of the role at all in his first audio diary. When I asked him about it in the telephone interview his immediate response was about his attitude to the role. It was only when I asked a direct question about self-care that the more usual mindful leisure activities and peer support were mentioned. I wondered why Patrick's default position to the question about emotional well-being was about mind set, i.e. proactive rather than reactive. I wondered if this was a fundamental difference between female and male nurses working in this environment, or whether it was particular to Patrick.

boundaries becoming 'blurred' due to repeated interactions and talking on a more personal level. However, he was very clear that his role was that of a friendly professional and not a friend.

*...you know, being friendly but not being friends and you know, what the, the very blurred lines that we have to contend with sometimes.*  
(Patrick, telephone interview 1, p.13).

Despite the predominantly informal relationship that Patrick enjoyed with Bryan's family and others, he felt that he was able to maintain professional boundaries by avoiding situations where a family could misinterpret informality for friendship. Patrick appeared to use the distinction between being friendly but not friends to illustrate how he navigated the 'blurriness' he refers to in his relationship with parents. Since 'blurred' can be defined as 'lacking clarity', it could be suggested that by differentiating between friendship and friendliness Patrick attempted to bring clarity to the nature of the relationship. To delineate the difference between his role as a friendly professional and a friend, Patrick used the example of making a decision on whether to accept an invitation to a birthday party based on whether he was being asked to provide clinical care for the child (which would be acceptable) or attend as a guest (which would not be acceptable). Thereby Patrick is clarifying his role as being that of the nurse who may interact on a social level within the hospice but would not interact socially outside the hospice unless it was alongside care provision.

#### **4.7.3. Purposeful self-disclosure**

Patrick highlighted another challenge to professional boundaries due to the nature of hospice work. This was in relation to staff being tempted to share too much personal information with families. Whilst he said he was mindful of limiting self-disclosure and altered levels in accordance with the relationship and situation, he did feel that sharing some personal information helped parents to build a picture of him as an individual, identify common ground and build trust, which helped him support them effectively. Further he referred to using self-disclosure to ensure that the conversation was not solely confined to the child's condition and the family's situation.

*...you know things that we have in common ..., yeah it's a two way street. In order to build up trust with, ..., gain trust from a family, you have to share little snippets of information about yourself and it's that sharing that allows them to sort of build up a trusting picture of you ... it can't all just be about the child. It can't all just be about their situation, you have to share some things that you have in common, some things that run parallel. (Patrick, telephone interview 1, p9-10)*

Patrick's rationale for revealing something about himself to build trust suggests an element of reciprocity. Parents will inevitably recount complex clinical and family information during their interactions with staff since the 'whole family' nature of CH provision necessitates it. However, I feel it is important to remember that the nurse is receiving this information as part of their job and often a tool, such as a form, will be used as a vehicle for gathering this information. In Patrick's case, when Judith was reticent about providing information, he used light-hearted banter with Nanny and Evie as a way of drawing Judith out. So he used self-disclosure as a means of smoothing the conversation to gain the information he needed. Further, Patrick's referral to self-disclosure as a means of preventing conversations being solely confined to the child's condition and the families' situation was interesting. This was perhaps his way of enabling parents to have a 'normal' conversation with someone who was fully aware of their circumstances but did not dwell on it, thus giving parents 'respite' from discussing their situation.

This may also be Patrick's way of redressing the balance between the level of information he had about the parents and what they knew about him. This is a slightly negative notion in that redressing the balance of information may be underpinned by ego. Most people like to talk about themselves and in everyday conversation there is a two-way exchange of information, in fact Patrick refers to this in the extract above. It may be that Patrick was subconsciously influenced by the homely, friendly, social environment in which he was undertaking these interactions, thereby adopting a more social style of conversation.

## 4.8. Summary

Across the six participants a total of nine stories were told. Each story was analysed using Braun and Clarke's (2006) six steps, firstly the audio diary and then threads followed to the telephone interview. At the individual level a total of 20 themes were identified. Each theme name is unique and was chosen to capture the essence of the participants' expression, my analysis and interpretation. Table 4.2 provides an overview of the individual participant themes. A number have similar meanings or a common approach to a specific aspect of the nurse-parent relationship. Others are counterbalances to emotional labour (self-styled methods or drawn from features integral to the hospice). These individual themes reflect components of emotional intelligence and the continuum of professional behaviour including boundaries, particularly efforts to avoid becoming overly or underly involved either on an emotional or relational level. Chapter 5 will present an analysis of themes which were identified in all or most of the participants.

<b>Table 4.2: Summary of individual participant themes</b>	
<b>ALEX</b>	<b>CHRIS</b>
<ul style="list-style-type: none"> <li>➤ It is their pain not mine</li> <li>➤ Separating the work me and the home me</li> <li>➤ Keeping it professional</li> <li>➤ Counterbalances to emotional labour</li> </ul>	<ul style="list-style-type: none"> <li>➤ Self-care strategies</li> <li>➤ Only my peers really understand</li> <li>➤ Balancing personability and professionalism</li> <li>➤ Competing priorities</li> </ul>
<b>LES</b>	<b>JO</b>
<ul style="list-style-type: none"> <li>➤ Keeping families at 'arms-length'</li> <li>➤ Buttoned up or burnt out?</li> <li>➤ Zero self-disclosure: avoiding the slippery slope</li> </ul>	<ul style="list-style-type: none"> <li>➤ Emotional barriers and self-control</li> <li>➤ Intrinsic counterweights to emotional labour</li> <li>➤ Self-disclosure: a difficult balance</li> </ul>
<b>ASHLEY</b>	<b>PATRICK</b>
<ul style="list-style-type: none"> <li>➤ Emotions: It's about them not us</li> <li>➤ They think we're their friends</li> <li>➤ Instinctive self-disclosure</li> </ul>	<ul style="list-style-type: none"> <li>➤ Strategies for managing emotional involvement</li> <li>➤ Being friendly but not being friends</li> <li>➤ Purposeful self-disclosure</li> </ul>



## **CHAPTER FIVE: WHOLE GROUP ANALYSIS**

### **5.1. Introduction**

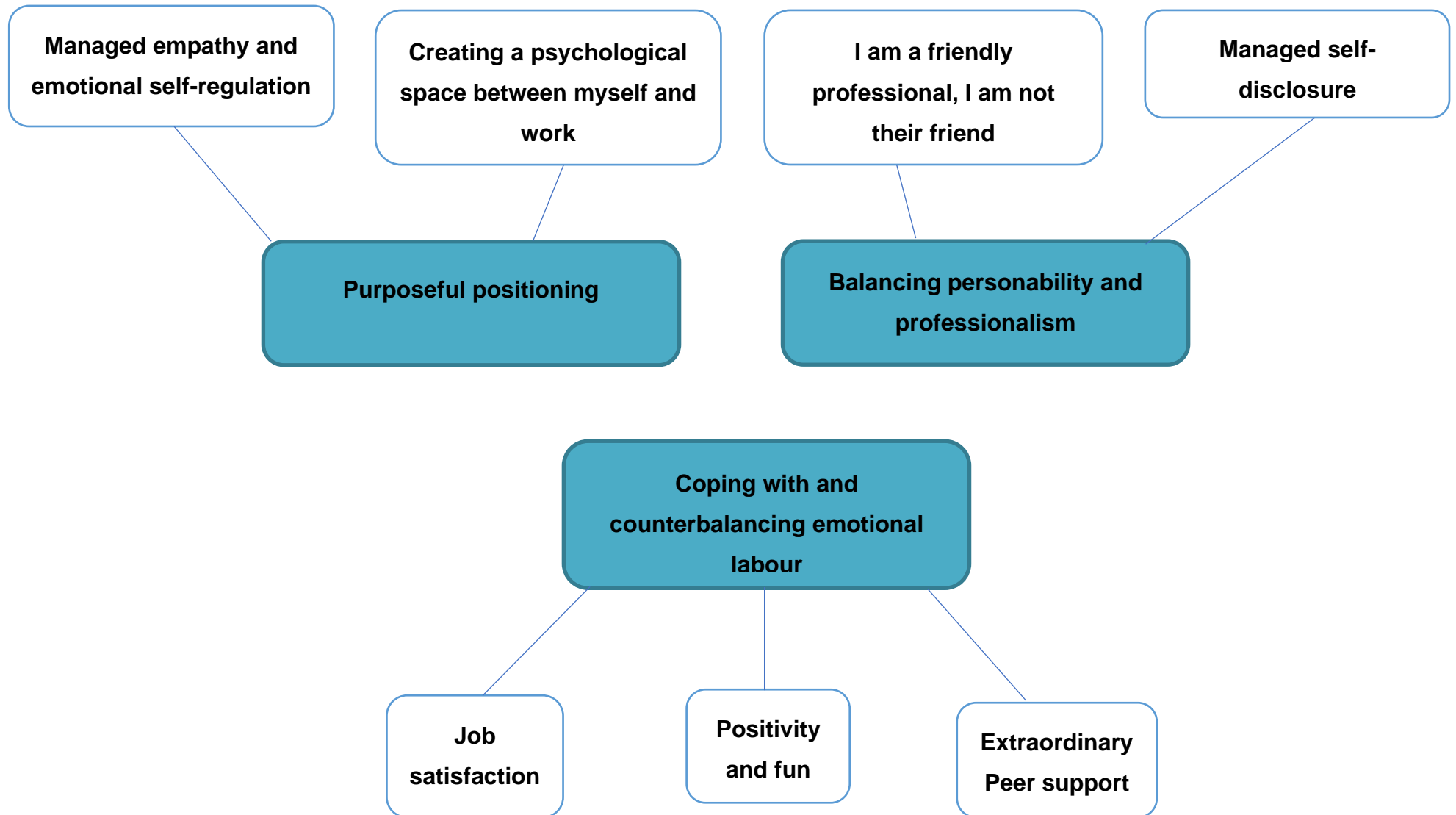
The themes identified in Chapter 4 were useful in providing an insight into the experience and practices of individual participants. Commonalities of approach to relationships with parents in the CH setting were apparent in the majority of participants. The aim of this chapter is to identify these commonalities and present them as themes which, in relation to the participants of this study, make a significant contribution to answering the research question 'How do children's nurse working in hospices manage emotional labour and professional integrity in long-term relationships with parents?'

The three overarching cross cutting themes were:

- Purposeful positioning
- Coping with and counterbalancing emotional labour
- Balancing personability and professionalism

Figure 5.1 illustrates the sub-themes associated with the themes.

**Figure 5.1: Whole group themes and sub-themes**



## **5.2. Purposeful Positioning**

### **5.2.1. Introduction**

I have used the word 'positioning' to identify this theme because although the participants often referred to emotional or professional 'barriers' between themselves and parents, the essence of what they described was more facilitative than a firm psychological barrier. Moreover, the word 'barrier' does not suggest that movement is possible and what participants described to me strongly suggested that they constantly refined their approach within and across their relationships with parents. This refinement involved moving closer, retreating and 'morphing' into a slightly different practitioner to meet a family's needs. So, a fluid, flexible approach which had been developed over time. Having named this theme I discovered that the phrase 'positioning' is used in marketing and that, in fact, 'Purposeful positioning' is a specific marketing strategy. I am certain that I had not heard it before, as much as one can be sure about what penetrates our sub-conscious. Clearly, this is not about marketing; it relates to skilful, flexible and active 'in action' and 'on action' navigation of 1:1 interactions. As I typed the phrases 'in action' and 'on action' I was reminded of teaching reflection to undergraduate students and although the participants did not mention reflecting in a formal sense, they did refer to it terms of thinking through their actions during the working day or afterwards.

### **5.2.2. Creating a psychological space between myself and work**

All six participants described ways in which they created space or distance between themselves and families. This occurred both during the working day and after their shift had ended. Temporal shifts which occurred at the end of the working day were sometimes accompanied by a physical action which seemed to help the participant make the psychological transition from work to life outside. So, for example, Alex described how the action of walking to her car with colleagues at the end of the shift and then using the time it took to drive home to mentally leave work behind and return to the mindset of being a wife and mother. Jo's creation of a psychological space between herself

and families did not include a physical action to help her transition from work to home but she clearly endeavoured to separate her work self from her home self by focusing her thoughts on home and making the most of family life.

Chris also created a psychological space for herself via deliberate acts outside of work; that is intentionally excluding nurses from her social circle so that work life and home life were entirely separate.

*So I've got a separate life to nursing and that's really good for my mental health I suppose because it keeps me grounded and I don't just surround myself with nurses, otherwise I would go insane I think, because that's all you would talk about because when you are with fellow nurses and your colleagues all you talk about is work but my social life doesn't involve that so I don't, I have a break from it.*

(Chris, telephone interview, p.4)

Whilst it could be argued that this strategy also fits with the counterbalances theme (Section 5.3), I have included it here because my interpretation of what Chris was referring to would commonly be known as some 'head space'. Likewise, Chris' other self-care mindfulness activities such as meditating and relaxing with candles would be ways of unwinding and ultimately clearing one's mind of thoughts of work. In the same way Patrick also undertook activities outside of work, which could be described as 'self-care', with the aim of 'clearing his head' of work. For example, walking by the sea and riding his bike, an activity requiring close concentration and therefore preventing him dwelling on work issues.

Psychological space created whilst at work sometimes also involved some sort of physical action. This removed the participant from the situation and allowed them to engage in an activity which was either distracting or facilitated a mindful space. The necessity of a physical action alongside a psychological shift is logical since it would be difficult to shift one's thoughts away whilst remaining engaged in the work activity which was the source of anguish. Examples of this are that Alex, Jo, Patrick and Ashley were able to take time out if they were starting to feel overwhelmed. This included activities such as going for a walk in the hospice grounds or to a quiet room to engage in some sort of activity. Although nurses in other clinical areas may

create a 'space' between themselves and work, even on good days, e.g. during a routine break or by volunteering to run an errand off the ward, the participants only referred to this type of 'time out' activity when they were managing their own distress. I would suggest that aside from the emotive nature of the work, 'time out' would be an important factor for many CH nurses since I am aware from my own experience, and as described by Ashley and Alex, hospice nurses often do not take routine breaks away from their care duties, i.e. refreshment and meal breaks are taken with the families in communal areas. Even on a very good day it must be difficult when the only private time you have to be alone with your thoughts, during the working day, is perhaps a toilet break.

Longer lasting psychological and physical space was created by Ashley and Patrick by physically distancing themselves from families. This was achieved by requesting that a family who were starting to intrude on thoughts outside of work be allocated to another nurse for a few shifts or by planned regular routine rotation of nurse: family allocation. This physical act of participants removing themselves from the family for a period of time appeared to facilitate a temporal break from the emotional labour of the situation which enabled them to 'regroup' and return to the situation with a more objective mindset.

However, creating a psychological space whilst in the workplace did not always involve a physical action. Alex used the metaphor of being connected to families by a bridge. She explained this by saying that it helped her to visualise the space between herself and families whilst remaining connected to them, i.e. with her on one side and the families on the other. As well as the space created by the span of the bridge, it may be possible that this imagery also depicted how Alex navigated the professional boundary (represented by whatever ran under the bridge) by using it as a means to advance closer to families when necessary and then retreat when she was no longer needed or when she felt she was becoming too involved. So, having created this space Alex was also literally 'bridging the gap' between herself and families when she needed to. These are useful images but I do

wonder how easy it is to retreat from a family once a nurse has become close to them.

Patrick's approach to creating a psychological space at work also involved a specific way of thinking about his role. I would describe this as being role focused rather than self-focused. This was demonstrated by what he described as the 'right attitude' to what he was trying to achieve in his role. So, concentrating on delivering high quality care that made a real difference to children and families and being content with the achievement of that goal, rather than engaging in mental angst about the tragedy of the situation.

*Well I think it has a lot to do with how you look at what you are trying to achieve and the best way I think I can explain it is, um, for children we're looking after there is no chance ... they're not going to get better, they are going to have shortened lives. So what we are trying to achieve with them ... is to give them the best quality care..... So I think it's all about the expectations that you have ...'*

(Patrick, interview 1, p.14-15)

Patrick's approach appeared to create a space between his role as a nurse and himself as a person (including the feelings he would have about the situation as a fellow human being) whilst at work. This is complex and, I would suggest, is easier said than done because, as articulated by Jo, separation is challenging because so much of what you do as a nurse relates to who you are as a person. Perhaps this way of thinking about the role is unique to Patrick within this study because he is the only male participant and gender differences may alter emotion management strategies. Alternatively, it may be a result of his personality, personal attributes or experience. Realistic suggestions would only be possible if the study were replicated with male only participants.

The most significant psychological space between a participant and families was in the way in which Les positioned herself. Her account of an 'arms-length' approach to working with families appeared to be ingrained in her psyche, possibly due to a career almost entirely spent in caring for children with life-threatening and life-limiting conditions. She did acknowledge that such an approach and her adherence to it might make her appear cold, but she did not express any desire to change. Unlike other participants she did

not view her relationships with parents as any different at the hospice compared to the hospital setting. Having explored the negative aspects of working in CPC via the literature review I suspected that, due to her prolonged work with life-threatened and life-limited children and their families, Les may be experiencing compassion fatigue and/or burn out and had subsequently psychologically withdrawn from them. Other possibilities are that Les had a fear of 'stepping over the line' because of some past transgression which had real or potential consequences. My reason for thinking this was that Les referred to having heard horror stories about others who had breached boundaries and then found it very difficult to return the nurse-parent relationship to a professional footing, calling this a 'slippery slope'. I wondered afterwards if these 'others' were, in fact, Les herself. However, I did not broach this with her at the time and, in fact, to do so would be quite confrontational as I would, essentially, be accusing her of being untruthful.

Returning to Alex's metaphor of being connected to parents by a bridge. In terms of the continuum along which the participants positioned themselves in creating a psychological space between themselves and work, it is perhaps useful to imagine it as a footbridge for most, extending to a lengthy suspension bridge for others. Nevertheless, the creation of what I have labelled 'space' between all the participants and families is achieved in a range of individual ways and for five of the six participants this is a flexible space, created using a range of thought process.

### **5.2.3 Managed empathy and emotional self-regulation**

I have used the phrase 'managed empathy' to identify what participants articulated about the internal dialogue they had about their feelings (during and after work) and how this enabled them to manage the internal management and external expression of emotions at work. Managed empathy differs from creating a psychological space because creating space implies a slightly defensive, self-protective stance of separation whilst the use of managed empathy is a more active, engaged approach to navigating the emotional demands of the role.

Participants often used the word empathy to describe their response to the emotive situations experienced by the parents they supported. My understanding of empathy was putting oneself in the other persons position and experiencing the same feelings. However, what the participants described when they explained empathy did not align with my understanding. This led me to explore empathy more fully and I found that different types were identified in the literature. These are discussed more fully in Chapter 6.

The accounts of Alex, Jo, Ashley and Pat enabled me to identify a subtle and skilful approach to configuring their thoughts about families, so that they could deliver compassionate care in an emotive situation without becoming immersed in it. Even when the participant did not necessarily use the word empathy, analysis of their account and identification of the essence of their dialogue revealed that they were referring to different ways of identifying with the families' situation.

*So I try and put myself in their situation ... I talk to them about how I would feel if I was in their situation rather than how I have felt in similar situations ... I think that's, sort of, that's that professionalism kicking in, in that I don't try and relate their situation to anything that I've experienced, you know their experience to my experience. I try more, sort of, ... you know, 'If I was in your shoes these are the things that I would be considering'. So I'm trying to, you know, keep the focus on their situation and the way they are feeling and about how I would look at things if I was in their situation, rather than how I have looked at things when I've been in a similar situation.*

(Patrick, telephone interview 2, p. 5).

In relation to the external expression of emotions at work, Alex, Jo and Ashley referred to professionalism in terms of hiding how they felt. However, I would suggest that it is only possible to display this outward 'professional face' (as it was referred to by Ashley) if the nurse has mastered the ability to suppress or set aside their emotions until they are in a situation where they deem it appropriate to release them. So, whilst the individual can still be seen by families they will be putting on a 'act' of 'business as usual'. Inducing or supressing feelings to present a countenance which reassures others is part of emotional labour but this may be even more challenging in a CH



environment where many activities are focused on having fun, so the nurse may be required to simultaneously suppress distress and induce joviality.

The undesirability and inappropriateness of displaying anything beyond becoming slightly tearful at work was highlighted by the participants, particularly Alex and Ashley. In essence this relates to the individuals' ability (or not) to self-regulate their behaviour.

*... you know it doesn't matter how bad we feel ... You know that's nothing compared to what it is for his nearest and dearest. I think it's about keeping that perspective really and not allowing, I think it's ok to show a bit of upset so long as you know ... (trails off) ... This social worker was sat sobbing on the settee all of the time. You know, and that's not right either. (Ashley, telephone interview 1, p.1-2)*

It is interesting that in the passage above Ashley trails off when trying to articulate how to manage her own feelings and how these are displayed. She is clear about her view on what is and what is not appropriate but not how this is achieved, suggesting that this is an innate attribute which may be difficult to convey. So, in instances where other practitioners displayed inappropriate levels of emotion (as identified by the participants) perhaps the inability to self-regulate behaviour was not the only factor. I wondered if these individuals were so involved with a family that they were almost experiencing the situation as if they were the parents, thus feeling such high levels of personal distress that self-regulation was impossible. This is the polar opposite of the individual themes identified for Alex and Ashley of 'It is their pain not mine' and 'Emotions: it's about them not us.'

So, a combination of being overly involved on an emotional level and poor emotional self-regulation could have led to the sort of behaviour exhibited by the social worker in the extract above. It could also be argued that poor self-awareness may have led to the social worker failing to recognise that she needed to move to a private space where she could release her emotions and then return if/when she was composed enough to offer support to the parent.

This is not to say that those who empathise at a reasonable level and self-regulate do not experience or display distress. For example, both Alex and Ashley referred to feeling emotional when witnessing parental distress.

*Shane (stepfather) was shaking and it was quite emotional watching him umm (pauses) and I felt my own eyes 'well up' a bit, not that I expressed that (participant sounds emotional) overtly but I was aware that I was feeling emotional too. (Alex, audio diary 1, p.2.)*

*...we were sort of slightly upset ourselves I suppose. Feeling a bit vulnerable but you know, at the end of the day, you've got a professional face to keep going ... it's about them and not so much about us. (Ashley, telephone interview 1, p.1.)*

However, this is clearly feeling emotional for the parents rather than as an individual who is directly and wholly affected.

#### **5.2.4. Summary**

Although participants had general 'rules' or approaches to how they positioned themselves in dealing with a family's emotions and their own, this appeared to be somewhat fluid in order to adapt and adjust to a family's needs. Creating psychological space and managed empathy were not mutually exclusive; a number of the participants (Alex, Jo, Ashley and Pat) used both approaches at different times and in tandem within the same situation. I would suggest that managed empathy is the slightly more refined of the two approaches as it embraces the inevitability of being emotionally affected by the work and successfully managing this, rather than seeking to set oneself apart from it. This may be why both approaches were used interchangeably as it provides a balance between keeping a distance and being involved, thus keeping the practitioner at a point whereby they are able to facilitate a professional therapeutic relationship.

I would suggest that some elements of emotional intelligence are encompassed within this theme in relation to internal management of thoughts and feelings and their external expression/repression, i.e. self-awareness, different levels of empathy and self-regulation of emotion and

behaviour. Moreover, I would suggest that the ability to adopt a flexible approach to emotive situations may be indicative of experience longevity in the nurses involved in this study. It could also be their level of skill or personality traits. However, the only fact I have in my possession is the length of experience in hospice work that my participants have, so I am only able to make suggestions on this basis.

### **5.3. Coping with and Counterbalancing Emotional Labour**

#### **5.3.1. Introduction**

In addition to the deliberate thoughts and/or actions of the participants (discussed in Sections 5.2 above and 5.4 below) their ability to manage emotional labour was often complemented and enhanced by intrinsic features of their role. The participants identified these intrinsic features as things which 'off-set' emotional labour or helped them to cope with it. These features were job satisfaction, positivity and fun and exceptional peer support. Although the participants did not use the term 'counterbalance' I have used it to identify this theme as I feel this captures the essence of what they described. So not erasing the emotional labour by covering it with something else, i.e. 'papering over the cracks' but acknowledging its existence and leaving it intact whilst simultaneously enjoying and embracing the positive elements offered by CH nursing. These positive features were reported as being abundant during the working day, whilst emotive situations arose relatively infrequently, resulting in many more good days than bad. Thus, enabling the participants to continue in their role.

#### **5.3.2. Job satisfaction**

The standard of day-to-day care which nurses were able to deliver and the opportunity to focus solely on one child and their family was referred to as a source of immense job satisfaction. Alongside this there also seemed to be a definite sense of pride in being able to use and develop skills to provide high quality care, support families and work in partnership with them, often over

long periods of time. These features of the role helped participants to contribute to ensuring the family and child's wishes were granted in terms of the ultimate aim of a 'good death'. Certainly, for a number of participants (Pat and Jo articulated this very strongly) the nurses' attitude to the role, in terms of shifting from the cure focused approach of previous roles to a philosophy of accepting the inevitable and making the family's 'voyage' to that destination as pleasant as possible was a great source of satisfaction.

Further Jo highlighted that CH nursing provided the time and resources to give the type and level of care that was difficult on ward areas due to inadequate staffing and the general routine of wards. So essentially high levels of job satisfaction appeared to help offset the emotional labour caused by the demands of complex care delivery for children with life-limiting conditions.

*For me it's the type of nursing that I love ... I mean when I worked on the wards ... it was 'I'm going to be there in a minute' and I wasn't going to be there in a minute and so as a nurse I wasn't achieving what I want to do and the hospice nursing gives me enough of a balance.*

(Jo, telephone interview, p.5)

So essentially what participants seemed to be articulating was that they were working within a service which was configured in such a way that it facilitated the achievement of its philosophy and aims of delivering bespoke 1:1 specialised care. Therefore, working within this environment was positive because participants anticipated that it was highly likely they would achieve what they set out to do when they arrived at the start of the shift.

Furthermore, this almost always proved to be true, thus giving a sense of satisfaction. It may not seem obvious that high levels of job satisfaction would directly correlate with counteracting the difficulties of emotional labour since they are not opposite sides of the same coin. Nonetheless they both evoke an emotional response in the individual, one primarily negative, or at the very least difficult, and the other positive. So according to the participants of this study, the emotional distress that they felt, although intense, was not usually frequent or constant. However, high levels of job satisfaction, a somewhat milder, quieter pleasurable feeling was almost constant and

therefore counterbalanced emotional labour. A good way of visualising this would be to imagine a vintage weighing scale with one large round metal weight on the platform representing emotional labour and the scoop on the opposite side full of many different items that bring happiness or pleasure to the individual nurse, representing multiple instances of job satisfaction. Each side of the scale is very different, but they are similar in weight. This does not in any way diminish the extent of the emotional labour but makes it bearable. That is not to say that the scale is in constant equipoise but overall there appeared to be a balance.

It may seem an obvious concept that a service is configured to deliver its own aims but Jo's referral to the realities of working in other, less well resourced, environments demonstrates that this is not always the case. Indeed, the contrast between other healthcare environments was one which I suspected would be relevant. Therefore, I sought participants who had previously worked in other clinical areas so they could compare their current situation with what they had experienced in the past.

### **5.3.3. Positivity and fun**

Aside from a sense of job satisfaction per se, four of the five participants referred to the hospice being a hugely positive place to work. Even Les, who had a rather stringent way of managing her relationships with parents, referred to having fun.

*...lots of fun elements because they are a fun family generally. So always laughter generally. (Les, audio diary, p.2).*

So in the same way that job satisfaction counterbalanced emotional labour, the positivity of the hospice philosophy and the enjoyment nurses gained from participating in fun activities alongside families had the same effect.

Even for the more serious and emotional elements of hospice work the underpinning focus was positivity. For example, Jo spoke about the focus on providing fun and a relaxed atmosphere during Andy's short stay accompanied by his best friend; despite the purpose of this visit being so that

his friend would feel comfortable visiting Andy at the hospice if/when he needed EoL care. This duality of extremes was further illustrated by Jo's general comment about hospice work.

*I think it's hard to explain isn't it, as you would know, to people who have never worked or had anything to do with a children's hospice that even when a child is dying, it's very sad but we will always try, as long as that's what the family are wanting, we'll always try to just carry on making memories and having fun..... you're just making those memories and having fun and doing as much as they can. But I think the balance is definitely on a personal level is good.... it's about giving them the opportunities that they might not have elsewhere and yeah making memories and taking pictures of them doing activities...*

(Jo, telephone interview, p.5.)

So, making memories with and for families was another part of hospice work which seemed to balance the emotional labour of the role and made the job such a pleasure to do. In some ways this is bittersweet because the underlying reason for focusing on making memories was a sad one but nevertheless enjoyable activities to be involved in. As well as Jo, Alex was particularly vocal about the enjoyment she gained personally from these activities.

So, the philosophy of day and short break care (on which the participants were asked to focus), of having fun and making memories, appeared to not only be delivered by the participants but they also seemed to become part of it. What I mean by this is that whilst it may be possible for a worker to act in a certain way while actually feeling something completely different, e.g. an unhappy shop assistant who 'switches on' an effusive demeanour when serving a customer. Although he/she may experience an uplift of mood following the pleasant customer interaction, since the duration of the communication is likely to be short and functional, this may not be substantial or lasting. However, CH nurses work, for extended periods, on a 1:1 basis alongside children and families while they engage in fun and memory making activities. Therefore, I would suggest that these factors alongside the therapeutic use of self, which is inherent to the profession, seemed more likely to elicit a fundamental and lasting positive feeling which helped to counterbalance negative emotions.

#### 5.3.4. Extraordinary peer support

Five of the six participants (all except Les) spoke about the value of peer support as a means of coping with the emotional demands of the role. Although peer support was not identified as a main theme for Patrick, he did mention both supporting and being supported by peers, primarily as a means of off-loading and letting off steam. However, Patrick's account did not suggest that the nature of peer support was fundamentally different to other areas in which he had worked. The main difference was the time available to spend on peer support activities. The availability of time within the working day was also highlighted by Alex, Chris, Jo and Ashley who, alongside this, outlined a level of peer support over and above anything they had experienced elsewhere.

Whilst it may not seem surprising that peer support would be significant given the nature of the speciality, the participant accounts did suggest that it was service delivery configuration that provided sufficient time within the working day to provide such support. So, the fact that children and families were looked after on a 1:1 basis alongside flexible routines meant that nurses had the time, as well as the inclination to support each other. Therefore, peer support almost always occurred on an ad-hoc basis where the mechanisms of giving and receiving were fluid and informal. Nevertheless, peer support did also occur in a more organised, routine way such as sitting in a circle at the end of the working day/night (separate to handover) and discussing the shift.

*At the end of our shift ... we all go around in a circle and say, 'how's your shift been' and most of the time we say 'oh it's been a lovely day' and there's this big dash to try and get home; but on that day and on other days when things happen it's almost intuitive that everyone wants to take a bit of time ... find out how each other felt ...*

*(Alex, audio diary 1, p.5)*

Since this was separate to the clinical handover it does, again, illustrate the time available and devoted to peer support activities and provides an opportunity to raise issues, if on that day, there was insufficient time to do so during the shift. Moreover, this activity seems to normalise the notion that

staff may have issues they want to discuss with their peers on a daily basis, rather than this being the exception, necessitating specific or separate individual arrangements (although, of course, this was available via clinical supervision and external agencies if the staff member required it).

The extract from Ashley below also indicates that the availability of time allows for a greater focus on and higher level of peer support.

*I think being in the hospice rather than the acute hospital setting, we as a team, have got more time to be supportive of each other ...you've got more time to be aware of each other's support needs and just vocalise your own feelings about how you feel things have gone and what your needs were and what you think we did well and what didn't go so well. (Ashley, audio diary 1, p.2)*

The overarching impression gained from the participant accounts was a sense of camaraderie, community, shared understanding and high levels of support which led to close bonds between staff. This was attributed to the uniqueness of the environment and lack of understanding of the speciality both by friends and family but also other healthcare professionals. So perhaps something of a 'huddle within a bubble', whereby the 'huddle' provided a means of ameliorating the emotional effects of the role and the membrane of the 'bubble' provided a protective layer to shield nurses, as much as possible, from the emotional labour of the role.

As highlighted, the majority of participants were engaged in giving and receiving peer support which was either exceptional in terms of the time devoted to it and, in four out of five cases, at an extraordinary level. However, having envisaged this as a 'huddle within a bubble' I wondered what became of staff who did not want to be part of or were excluded from this 'inner circle'. For example, Les did not even share happy news with her peers and did not mention peer support in her narrative of the shift or during the telephone interview. Perhaps those who are not involved seek support from elsewhere in order to cope with the emotional demands of the role, but to choose not to be included in what seems to be a highly valued and effective support mechanism seems strange. One could argue that perhaps this was not a feature of the hospice within which Les worked but my records



show that she worked for the same hospice group as Jo and Pat, albeit on a different site to Jo (Pat worked across both sites). Therefore, it is unlikely that this level of support was not available to Les. Since she did not mention peer support, I do not know the reasons why this was not a feature of her coping. This does not, however, suggest that she was not coping with the emotional demands of the role.

### **5.3.5. Summary**

The trio of positivity and fun, job satisfaction and extraordinary peer support that were part of the participants' daily work at the CH were either not experienced elsewhere or were in excess of what they were used to. These factors appeared to provide a consistent counterbalance to the emotional demands of the role and/or helped participants cope. Furthermore, singularly or in combination these aspects of the role appeared to help make the emotional demands of the work not just manageable but made the participants' jobs highly rewarding and enjoyable. Generally, I would suggest that benefitting from the counterbalances outlined in this section would inevitably depend on the extent to which nurses experienced job satisfaction and enjoyment or engaged in peer support. Nevertheless, for five of the six participants in this study the level of reward and participation was sufficient for these benefits to be highlighted within their narratives. That is not to say that their personal choices and individual coping styles did not also play a part in counterbalancing emotional labour.

## **5.4. Balancing Personability and Professionalism**

### **5.4.1. Introduction**

Providing a friendly, welcoming service in an environment designed to mimic a home, whilst retaining a professional stance was a juxtaposition which provided a challenge to most participants. They were aware that the hospice philosophy and environment could potentially carry them in a direction which would conflict with their professional role. Five of the six participants noted

that they needed to be vigilant to ensure that they were not swept along on the 'tide' of informality and sociability which underpinned the service.

I selected the noun personability, i.e. the quality of being personable, to identify this theme because I felt it conveyed what the participants were telling me about the difference between the CH and other care environments. They had, of course, had cordial conversations with parents elsewhere but the hospice philosophy of providing a homely environment and the length of time nurses could spend working 1:1 with parents was identified (by five of the six participants) as requiring a persona which was more hospitable and amiable than elsewhere. This did not prevent the five participants who identified this issue from maintaining a professional nurse-parent relationship, but they identified that it was a different type of professional relationship and required skilful navigation.

#### **5.4.2. I am a friendly professional, I am not their friend**

As stated, five of the participants identified that it was often difficult to strike a balance between being sociable and personable whilst maintaining professionalism. All participants were mindful of boundaries and NMC requirements (although they didn't mention specifics within the code), sometimes referring to a 'line' that they would not cross. Nevertheless, their perception was that parents sometimes viewed them as friends. Chris and Ashley saw this as particularly true for parents of children with very complex needs and whose lives were 'full' of professionals either visiting their home or seen at healthcare facilities. The five participants who spoke about balancing the social elements of the role with professionalism used the phrase chosen to label this sub-theme (or something very similar) to underline the difference between being friendly and real friendship.

Another issue which highlighted the difficulty in balancing the professional role with its social elements was that of socialising with parents, in some way, outside of work. Alex spoke about avoiding 'befriending' parents on social media platforms, a behaviour some of her colleagues engaged in and she felt pressurised to do. Patrick spoke about a commonly occurring scenario whereby a child was having a birthday party and the parent invited staff to

attend. He outlined the need for clear delineation between a work and social interaction in terms of the parents' perceived role of the nurse in attending the party. If this was to care for the child in a professional capacity then that was acceptable, whereas attending as a guest was not. Three (Ashley, Patrick and Jo) of the six participants were explicit about not socialising with parents outside their working hours and if they did happen to meet parents whilst they were off duty, the conversation would be very brief. I would suggest that this is an easier 'line' to draw since the encounter was away from the hospice environment. Nevertheless, if the last hospice-based nurse-parent interaction was informal, perhaps chatting during a meal or sharing a joke whilst watching the television, then subsequently adopting a more distant demeanour may be challenging. Moreover, if the parent does view the nurse as a 'friend' and does not appreciate that the social interactions at the hospice are part of the 'service', a formal interaction may leave them feeling somewhat bewildered or even offended. Therefore the 'reach' of the hospice, in this scenario, may extend beyond the walls of the building, highlighting why professional boundaries are seen as a challenge. This may be particularly difficult for those who live and work in the same geographical area.

Despite Patrick's clear delineation between being friendly and a friend there did appear to be a slight contradiction within his first account, in that alongside this he did use the word friend to describe the nature of the relationship with the family in the first story.

*... a friendly relationship with Nan, that helps the Mum see me as a family friend. (Patrick, telephone interview 1, p.10)*

*... I think that you find that when you're working with somebody for a very long time you become part and parcel of the family.*  
(Patrick, telephone interview 1, p13-14)

The first extract suggests that this is the family's perception of him rather than his of them. However, Patrick had already said that his role was about being friendly rather than a friend, so why would he want Judith (mother in his first story) to see him as a family friend? The second extract seems to imply that he sees himself as part of the family which would be beyond the

confines of the nurse-parent relationship. However, I did wonder whether this was exactly what he meant. We did not explore this further in the telephone interview so I cannot be certain, but I did get a sense that what he meant was that he became a 'feature' of family life (particularly as he cared for Bryan in his home as well as at the hospice) rather than a part of the family per se. I would suggest that it is the subtle difference noted here which illustrates the 'fine' line negotiated by nurses who work with families at the hospice for extended periods of time. This may also be influenced by the PR narrative from CHs generally (fund raising) and for nurse recruitment campaigns, since these invariably mention becoming either part of the hospice family or part of the child's family. So, although an objective viewer may see this as PR rhetoric, if a nurse is surrounded by this it may be difficult to remain separate from it. Likewise, parents who see or hear this type of language may have certain expectations of the level and type of relationship they have with staff.

#### **5.4.3. Managed self-disclosure**

For five of the six participants, the nature of conversations that they had with parents appeared to be closely linked to the theme of being friendly but not a friend and also influenced by the homely, social nature of the hospice environment. Alex, Ashley, Jo, Chris and Patrick were happy to share superficial personal information with parents but noted that personal disclosure required careful management. Les did not share anything, even a tenuous commonality, e.g. having visited a holiday destination planned by the family. Alex, Ashley and Patrick noted that the depth of information shared (although still labelled by them as superficial) would depend on the family, the circumstances or the length of their relationship.

Ashley and Patrick identified that the purpose of sharing personal information was that it helped parents to see them as an individual and this assisted in building a rapport. Patrick also felt that it was a good way to build trust and of

redressing the one-way information flow from parent to nurse.<sup>12</sup> Similarly Alex highlighted that sharing commonalities with a family was a means of making a connection with them.

*...you do share some things don't you, like you might talk about perhaps my kids. I've taken the kids to a concert or something as a way to connect um or you might share something which was perhaps a commonality... perhaps about a school or something.*

(Alex, telephone interview 1, p17-18).

However, Alex was mindful that even something which, on the surface, was innocuous, e.g. recounting a family visit to a theme park, could highlight the disparity of experience between her children and those in her care. Particularly if this was an activity which would not be possible/suitable for that particular child. Thus, underlining the need for careful selection of what is said and to whom.

So, in terms of what was felt to be acceptable superficial information that could be shared, Alex, Chris, Jo, Patrick and Ashley were all comfortable with families knowing that they had children and Ashley was happy to share information about a family event such as a wedding. However, Patrick identified that the family in story one, to whom he classed himself as 'close', knew more about his children than others. So, for example, he identified that he adopted a strategy of drawing out the slightly withdrawn mother in his first story (to obtain information relevant to the child's care) via conversations with 'nanny'. So perhaps he revealed more to get more. Thus, posing the question of whether he had a closer relationship with the family because he disclosed more or if he disclosed more because of the closeness of the relationship. In contrast, he edited the information shared with the family in story two

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<sup>12</sup> Extract from reflective diary 23.3.20: It strikes me that this slightly contradicts the notion of the therapeutic relationship, in that the nurse is receiving the information so that they can care for the family rather than engaging in a relationship which is reciprocal. This makes me wonder whether, when the participants felt that parents viewed them as friends, despite stating that they did not view the parent in the same way, they felt obliged to share some personal information (as you would when talking to a friend).

because the mother often 'gossiped' about the child's home carers/other families and he feared that the superficial personal information he revealed would be shared elsewhere. This was also true of Ashley who identified that should her instincts about a family be misjudged she could become a source of gossip, thus making her feel vulnerable.

With most families Patrick kept conversations to things that he classed as 'neutral' topics such as pets. However, Chris identified that she would talk about any topic but that this was essentially 'small talk'. Jo had similar views but although both were happy to disclose that they had children and their ages, neither would reveal information they deemed too personal, e.g. the names of their children. So, this 'small talk' did include some superficial information about their families rather than a neutral topic such as the weather. It appears that as well as individuals being willing to disclose different levels of information, there was also a difference in participants' definition of what constituted 'small talk' or neutral topics. This was compounded by an almost felt obligation in some (Chris and Jo) to answer personal questions. Even if they were not entirely happy to share this information, they would be reluctant to refuse because the philosophy of the hospice was to make parents feel welcome and comfortable. Further, the long-standing friendly relationship with a parent of a child whose life expectancy was limited seemed to make it difficult for Chris, Jo and Patrick to rebuff questions because it almost felt surly to do so. This may suggest that although parents are in the nurses' environment, where traditionally the 'power' and influence lays with the professional, in the case of the CH, the philosophy of care may alter the power/influence dynamic in favour of the parent. So, although, if pressed Jo, Chris and Patrick felt they could usually manoeuvre the conversation to avoid deeply personal enquiries. Patrick, would 'fall back on' referring to hospice policies as a reason for not answering a very intrusive question, even if there was no such hospice policy. Thereby moving the reason for the rebuff to an external, impersonal entity rather than directly from himself. This infers that it is the organisation that is rejecting the intrusion rather than him personally which is less likely to cause offence and damage his relationship with the parent. As a secondary thought he mentioned the NMC Code but did not state that he would refer to

this when declining to answer. It was interesting that he chose the hospice policy as a means of deflecting intrusion rather than the regulations covering his profession, as this would have also depersonalised the rejection. Perhaps this was because the hospice philosophy was the reason why he would find himself in such a situation and therefore using the organisation as a means of opting out seemed more logical.

In contrast Les' method of deflecting personal questions involved referring directly to the professional role of the nurse. However, as mentioned, Les was distinctly different to the other participants in that she did not share any level of personal information with parents.

*Come on now, I can't be telling you that, I'm your nurse!*  
(Les, telephone interview, p.8).

Nevertheless, Les identified herself as chatty and kept the conversation flowing by talking about things that related to the family, keeping conversations very much in the present, rather than talking about the past or future. Les' account suggests that she felt it was possible to be personable without disclosing personal information. Although she was the only participant who indicated that sharing personal information was totally undesirable both on a personal and professional level, this led me to wonder if, for the other participants there were other factors involved in influencing personal disclosure. The other five participants had clearly identified that their relationships with parents at the hospice were different to other clinical areas (whereas Les specifically stated that there was no difference). So, starting from this different 'footing' and with an acknowledged willingness to share some personal information perhaps the length of 1:1 time spent with families meant that neutral topics of conversation were soon exhausted and so progression to the more personal was somewhat natural and seamless. In contrast, for Les this was a line she had deliberately drawn and would therefore keep returning to neutral topics or shut the conversation down with her polite, slightly jokey but firm rebuff.

There could be an exponential escalation for participants like Patrick and Ashley who, from the outset, had the intention of sharing personal information as a means of building a therapeutic relationship (whereas for

Alex, Jo and Chris this appeared less deliberate and more of an organic consequence of general conversation). Nevertheless, if the 'baseline' was to share personal information I wondered how far this could potentially extend. However, in the case of Patrick and Ashley it is notable that they were the two older and the most experienced nurses, so perhaps time and experience has led them to a place where they are able to deliberately share personal information in such a way that they were confident it was safe to do so. This might be due to the manner in which the information is shared, perhaps a subliminal indication that it remains between them, or the careful selection of what is shared with whom.

#### **5.4.4. Summary**

Participants identified the challenge posed by the requirement to provide an environment which was as akin to home as possible, whilst continuing to maintain a professional stance in their interactions with parents. Put simply the expectation appeared to be to portray relaxation and behave as if they were at home, whilst at work, but when doing this they were required to think like a professional and undertake clinical duties commensurate with their nursing role. So essentially social interactions within a professional care environment. This is a duality which the majority (5 of 6) participants identified as being specific to the hospice environment and which was difficult to operationalise, because what was required was the opposite of what is usual for nurses. What I mean by this is that usually the 'professional face' is foremost with minor glimpses of the person. Whereas what the majority of the participants were describing was the nurse as a person at the forefront of their interactions with parents while the 'professional' is a constant but in the background <sup>13</sup>. These challenges presented themselves in two distinct but related ways; managing personal disclosure and being a friendly professional rather than a friend.

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<sup>13</sup> N.b. This is solely in relation to short break and day care which were the basis for the stories told by participants. Interactions involving symptom management, crisis management and end-of-life care would inevitably mean that the nurse as a clinical professional (in the traditional sense of the role) would be at the forefront of interactions.



Participants identified different levels and types of disclosure for different families. This was dependent on both the relationship and the families' circumstances. Disclosure was sometimes used proactively to forge the relationship, establish trust, give a sense of 'normality' and obtain information. Participants occasionally felt slightly pressured into disclosing information, or certainly not refusing to answer a direct question, due to the nature and circumstances of the families in their care and the philosophy of providing a homely environment. One participant did not engage in personal disclosure at any level, labelling it as a slippery slope which would make regaining a professional footing extremely difficult.

The philosophy and aims of the hospice also introduced factors which influenced the nature of the nurse-parent relationship. The social nature of some interactions meant that the relationship had a slightly different dynamic to the usual nurse-parent relationship. This led five of the six participants to suggest that families may see them as friends as well as their nurse. This was particularly felt to be the case in parents who were somewhat socially isolated and whose adult-to-adult interactions were mainly with health or social care professionals.

The concepts which underpin the sub-themes of 'Balancing personability and professionalism' suggest that the duality described by most participants required high levels of self-awareness and well-developed social skills. The approach described was somewhat flexible but less so than described in 'Purposeful positioning'. I would suggest that although both relate to 'self-protective' strategies, personability and professionalism are more overt and perhaps more objectively observed than the internal management of thoughts/emotions and how these are repressed.

## **5.5. Conclusion**

This chapter has presented themes identified in the stories told by study participants. Although her views were different to the other five participants Les' contribution to these themes was valuable because she demonstrated the extent to which the strategies and behaviours within a theme could range. The themes presented here demonstrate a range of factors which enable

nurses to navigate the emotional demands of hospice work whilst maintaining professional integrity in their relationships with parents. Those discussed under the 'Purposeful Positioning' and 'Balancing Personability and Professionalism' themes are strategies which are dependent on internal mechanisms and strategies employed by the nurse, whereas the sub-themes which make up the 'Counterbalancing and Coping with Emotional Labour' theme outline features of the CH nurses' role that contribute to ameliorating its demands.

## CHAPTER SIX: DISCUSSION

### 6.1 Introduction

Chapters Four and Five reported on the analysis stage of this study firstly in relation to individuals and then the whole group. A thematic analysis approach was used (Braun and Clarke 2006). Three main themes were identified, each with sub themes which are shown in Table 6.1.

<b>Table 6.1: Themes and sub-themes<sup>14</sup></b>	
Theme	Sub-Themes
<i>Purposeful positioning</i>	<i>Creating a psychological space between myself and work</i>
	<i>Managed empathy and emotional self-regulation</i>
<i>Balancing personability and professionalism</i>	<i>I am a friendly professional; I am not their friend</i>
	<i>Managed self-disclosure</i>
<i>Coping with and counterbalancing emotional labour</i>	<i>Job satisfaction</i>
	<i>Positivity and fun</i>
	<i>Extraordinary peer support</i>

In relation to the research question and aims (Box 6.1. below), data collection and analysis allowed me to identify the themes and sub themes in Table 6.1 which provide an overview of how the participants used a range of strategies and approaches to manage their relationship with parents in terms of their emotions (*Purposeful positioning*) and interactions (*Balancing personability and professionalism*). In addition to individual strategies and approaches, the participants revealed other factors which helped them cope with the demands of their role (*Coping with and counterbalancing emotional labour*). The overarching and fundamental essence of the three themes is achieving a balance or ‘happy medium’.

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<sup>14</sup> When themes and sub-themes are referred to within the discussion they will appear in italics. This is to provide clarity between the themes and theoretical model labels/titles.

### **Box 6.1: Research question and aims**

- ❖ How do children's nurses working in hospices manage emotional labour and professional integrity in long term relationships with parents?

#### **Aims:**

- ❖ To develop an in-depth understanding of how children's nurses manage long term relationships with parents in the children's hospice setting.
- ❖ To develop an in-depth understanding of how children's hospice nurses maintain professional integrity whilst providing long term practical, emotional, social and spiritual care to parents.
- ❖ To explore the coping strategies and protective factors used by children's nurses to manage emotional labour whilst working in the children's hospice setting.

The aims of this chapter are to discuss the findings from a theoretical perspective, demonstrate their application to CH practice and seek to identify the unique contribution made by this thesis. I will meet these aims by discussion of the findings through the lens of Emotional Intelligence (EI) which is defined as

*the ability to monitor one's own and other people's emotions, to discriminate between different emotions and label them appropriately, and to use emotional information to guide thinking and behavior.*

(Salovey and Mayer 1990, p.189)

This discussion will include selected verbatim extracts to illustrate some points and keep participant voices at the centre of the work. I will make suggestions for how the synergy of CH nursing and EI theory could be used to make improvements to recruitment, retention, formal nurse education, practice and staff development.

#### **6.1.1. The selection of EI: Process and Rationale**

The process of identifying EI theory as a lens through which to discuss the findings is outlined in Appendix 13. In addition to these considerations, the claim that EI is important for effective, quality leadership (discussed in

Section 6.2.2. below) also played a part in this decision. This related both to the longevity of experience of my participants and to nursing as a profession per se. As stated, the nurses in my study were experienced (they needed to have been qualified for at least five years to meet the inclusion criteria but in fact the minimum length of registration was 15 years). Some were in clinical leadership positions such as team leader, others were not. Nonetheless wherever a nurse is in the hierarchical structure they are accountable for their own practice, often work autonomously and act as role models to students and their peers. So, they are leaders, whatever the context; a fact acknowledged by the teaching of leadership skills in undergraduate nursing programmes. Therefore, exploring the study findings through the lens of EI is not only valuable as a means of shedding light on the findings but also for how this may be applied to practice within the CH setting, the wider CPC context and the education and development of children's nurses in a range of fields and hierarchical levels.

## **6.2. Emotional Intelligence Theory**

### **6.2.1. The concept of EI**

The concept of EI first arose in the 1960s (Leuner 1966). The idea that Intelligence Quotient (IQ) did not fully explain cognitive ability was proposed by Gardner (1983) who introduced the notion of multiple intelligences which included interpersonal intelligence (ability to understand another's intentions, motivations and desires) and intrapersonal intelligence (capacity to understand oneself, to appreciate one's feelings, fears and motivations). Beasley (1987) introduced the term Emotional Quotient (EQ) which has the same meaning as EI and used interchangeably. EI theory was significantly expanded by Salovey and Mayer (1990) who proposed that rather than emotion having a negative effect on reasoning, when properly directed, it could be productive and positive. Goleman (1995) further expanded on this and continues to be a prominent EI theorist. The primary focus of developing EI theory and research has been the link between high EI and ability to manage work demands successfully (Bar-On 2002), particularly in leadership roles (Goleman 1998). It is not suggested that EI is a replacement for metrics such as IQ or practical/technical skills measurement but considered

alongside as something which enhances performance, particularly in interpersonal interactions. The development of EI and its application to the workplace is paralleled by the evolution of performance management, particularly the introduction of individual objectives linked to organisational goals (Armstrong 2017).

### **6.2.2. Critiques of EI**

The three main criticisms of EI are that it is poorly defined and measured, it is just a new label for older constructs and its importance has been inflated (Murphy 2013). However, I would argue that whilst constructs of EI may appear a little nebulous, definition and characteristics within individual models provides clarity. The claim that EI does not lend itself to measurement is a fairer one. It is difficult to measure because, although behaviours can be observed and judged, much of what occurs involves internal processes. This is difficult to quantify, even for the person who is undertaking these thought processes. However, there are validated tools, for example Mayer et al. (2002), Petrides (2009) and Boyatzis et al. (2017). Claims that EI is a new label for older constructs may be valid but I would suggest that the evolution of theories and concepts is positive because fresh eyes bring new perspectives which can enhance seminal concepts. Furthermore, their presentation using contemporary language will appeal to new audiences. I do not think it matters if something is rebranded/ repackaged provided the original contribution has been acknowledged. The suggestion that EI has been overinflated is debatable. This was primarily targeted at Goleman's book title *Emotional Intelligence: Why it can matter more than IQ* (1998 – 2020). However, EI supporters do not claim that it is singularly important, merely that it is useful for relationship management. The only overarching claim that theorists make is that those who excel in leadership roles demonstrate EI (Goleman 1998). These claims have been tested via empirical research (Gardner and Stough 2002; Issah 2018) and found to be valid in terms of a correlation between EI and transformational leadership.

### 6.2.3. EI models and frameworks

There are several theoretical frameworks of EI such as the Trait (Petrides 2011), Ability (Mayer and Salovey 1997; Mayer et al. 2004) and Mixed Models (Goleman 1998). The Trait Model is a self-report framework which measures an individual's self-perception of their emotional abilities. This would be more suited to collecting data for a deductive study rather than interpreting data elicited for a qualitative study such as mine. The Mayer et al. (2004) ability model has been used in nursing research, but this is a framework for observed assessment of ability and is therefore also more suitable for deductive studies than as a framework to explore my data and findings. Goleman's Mixed model (1998) provides a broad outline of skills and competencies which initially appeared suitable to discuss the findings of this study. His skills and competencies model (Table 6.2), has five main constructs.

<b>Table 6.2: Goleman's constructs of Emotional Intelligence</b>		
Type of Competency	Construct	Definition and Characteristics
Personal competencies (intrapersonal intelligence): knowing and managing emotions in oneself	Self-Awareness	the ability to know one's emotions, strengths, weaknesses, drives, values and goals and recognise their impact on others while using gut feelings to guide decisions.
	Self-Regulation	self-control, controlling or redirecting one's disruptive emotions and impulses, respond rather than react, think before acting, comfortable with ambiguity and ability to adapt to changing circumstances, trustworthiness and integrity.
	Intrinsic motivation	a passion to work for reasons beyond money or status, an awareness of personal motivators, optimism and perseverance in the face of adversity, organisational commitment.
Social competencies (interpersonal intelligence): knowing and managing emotions in others.	Empathy	ability to understand other people's emotions and reactions (only possible if self-awareness is achieved) considering other people's feelings especially when making decisions.
	Social Skills	managing relationships to get along with others, communication skills, finding common ground with others, building a rapport, conflict management.
(Adapted from Goleman 1998)		

Boyatzis et al. (2000) reduced these five constructs to four emotional competencies; Self-Awareness, Self-Management, Social Awareness and Relationship Management. Cherniss and Goleman (2001) developed this into a framework for emotional competencies with additional 'Recognition' and 'Regulation' labelling (Table 6.3.).

<b>Table 6.3: Framework of Emotional Competencies</b>		
	<b>Self Personal Competence</b>	<b>Other Social competence</b>
<b>Recognition</b>	<b>Self-Awareness</b> Emotional self-awareness Accurate self-assessment Self-confidence	<b>Social Awareness</b> Empathy Service orientation Organisational awareness
<b>Regulation</b>	<b>Self-Management</b> Self-control Trustworthiness Conscientiousness Adaptability Achievement drive Initiative	<b>Relationship Management</b> Developing others Influence Communication Conflict management Leadership Change catalyst Building bonds Team- work and collaboration
(Cherniss and Goleman 2001)		

Whilst these additional labels are useful, some of the competencies in this framework apply to relationships with colleagues or organisational leadership rather than relationships with those who are served by the organisation. This is perhaps indicative of the business background of its authors. Furthermore, the loss of 'Empathy' and 'Intrinsic Motivation' as separate constructs make this framework less suitable for application to a care setting than the original Goleman (1998) version. Moreover, the allocation of the Empathy construct to the 'Recognition' section of the framework is at odds with my findings, i.e. that using appropriate levels of empathy requires 'Regulation'. Identifying this also highlights that 'Empathy' may not just be a social competence (interpersonal) of recognising and managing emotions in others but also a personal competence (intrapersonal) as it involves knowing and managing emotions in oneself. This is acknowledged in Goleman's (1998) model, i.e. empathy is only possible if self-awareness is achieved, but if the competency of 'Empathy' sits solely within 'Social Awareness' as it does in the Cherniss



and Goleman (2001) model, the link between empathy and self-awareness (and therefore regulation) becomes lost.

So, in the absence of a model which fully fits my findings, for the purposes of this discussion I have stripped Goleman's original model back to the construct titles of Self-Awareness, Self-Regulation, Intrinsic Motivation, Empathy and Social Skills. However, I will later suggest a framework for using EI which is suitable for CHs. This will combine my study findings with useful elements of the models outlined above, so that colleague and patient/client relationships are blended within the same framework.

### **6.3. Exploring the study themes through the lens of EI**

#### **6.3.1. Purposeful positioning through the lens of EI**

As discussed in Section 5.24 the study participants used two main approaches to manage the emotive aspects of the nurse-parent relationship, i.e. *creating a psychological space between myself and work, managed empathy and emotional self-regulation*. These differ because the first is a distancing strategy whilst the second requires controlled involvement. This is in keeping with the notion that EI is not about suppressing emotions but recognising and managing them (Megías-Robles et al. 2019). These approaches were used at different times and in tandem within the same situation. So, a fluid and flexible approach was used in the management of the emotional relationship the participants had with parents. However, Les' approach was primarily distancing, less flexible and highly self-regulated. The deep and complex facets of managing the emotional aspects of the nurse-parent relationship relate to internal management of thoughts and feelings and their external expression/repression. All of which are indicative of the link between emotional labour in nursing and EI (McQueen 2004). So, the ability to adapt to changing circumstances and uncertain disease trajectories (Hain et al. 2012), maintaining a distance, advancing and retreating, depending on the parents' needs (described by Hendersen 2001 as an emotional labour 'tango') suggests that the participants self-awareness and self-regulation skills were highly developed.

*...you do see some really terrible things and situations and if you took them all on board you might crumble yourself, mighten you. So I try and keep that sort of a bit of a bridge, you know. [Alex]*

Difficulties in navigating the nurse-family relationship and maintaining a balance between over and under involvement were highlighted in the literature review (Woolley et al. 1989; Benner and Wrubeln 1989; Totka 1996; Maguire and Price 2007; Roberts et al. 2015), even for experienced nurses (Cargill 2014). My findings and their discussion through the lens of EI provides an understanding of how a number of experienced CH nurses managed these challenges. This is important because working in CPC can lead to compassion fatigue and burnout (Maytum et al. 2004; Kase et al. 2018) if nurses become weighed down by the emotional demands of the role and are unable to separate themselves from work.

Alongside self-awareness and self-regulation, grades of emotional involvement (identified as '*managed empathy*') was a feature of the *Purposeful positioning* theme. Goleman (1995) describes an empathetic individual as someone who can understand and cope with another's sadness and hardship. He highlights the EI construct of self-awareness as a pre-requisite for empathy. A substantial aspect of the analysis was identification of different levels of empathy based on my interpretation of what the participants deemed to be appropriate and inappropriate levels of emotional involvement and behaviour. Three types of empathy: cognitive, compassionate (desirable) and emotional (undesirable) were outlined by Goleman et al. (2017).

Cognitive empathy allows the individual to see a situation and the associated feelings from the other person's perspective which can be useful in business meetings and negotiation. However, this type of intellectual understanding in isolation is primarily dispassionate (Goleman 1995). Compassionate empathy enables the individual to feel 'for' the other person and elicits a desire to help or support. Essentially compassionate empathy is a middle ground between cognitive and emotional empathy and described by Goleman (1995) as the 'ideal'. The compassionate empathiser does not get 'sucked in' and take on the other persons feelings or burden; they simply understand, care and help.

Emotional empathy is at the opposite end of the scale to cognitive empathy. Goleman (1995) defines emotional empathy as physically feeling alongside the other person, almost as if their emotions were contagious. Emotional empathy or empathy imbalance (Cross 2019) can lead to burnout and compassion fatigue. Furthermore, professional behaviour can be compromised if self-regulation skills are poorly developed (Goleman 1995). For example, as illustrated in Ashley's rather derisive description of the social workers behaviour.

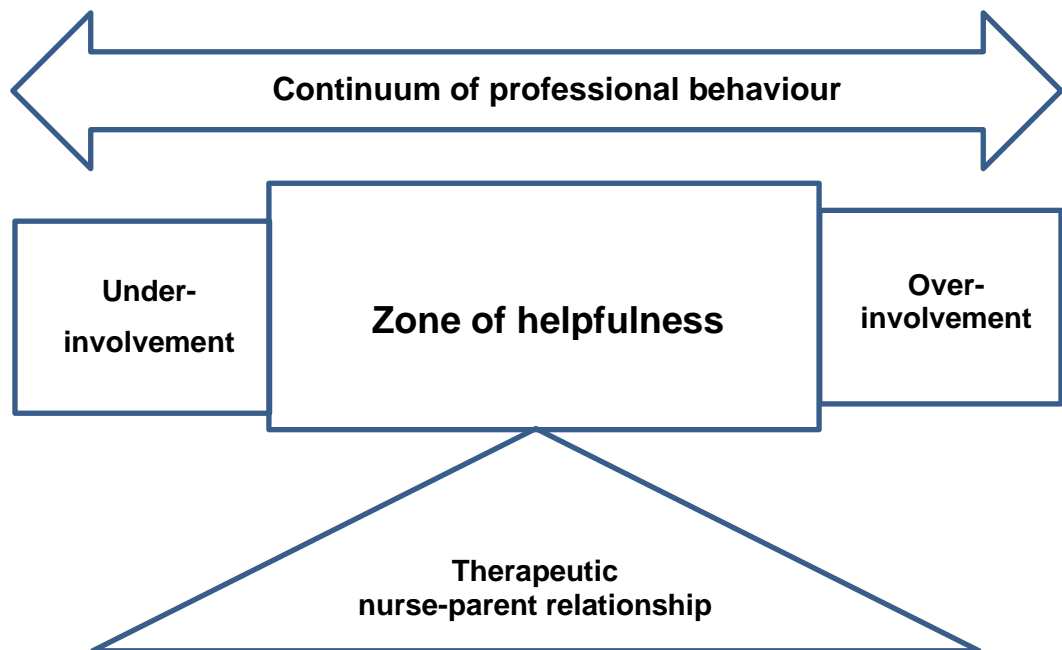
*This social worker was sat sobbing on the settee ... that's not right ... It's not for you to be a heap of jelly in the middle of trying to manage what is a terrible situation for them. [Ashley]*

So, by seeming to employ cognitive and compassionate empathy but not emotional empathy the participants were able to respond rather than react to parents' emotional behaviours. Thus, aiding their ability to self-regulate.

*I don't try and relate their situation to anything that I've experienced, you know their experience to my experience... So I'm trying to, you know, keep the focus on their situation and the way they are feeling and about how I would look at things if I was in their situation, rather than how I have looked at things when I've been in a similar situation. [Patrick]*

The interchangeable use of distance and involvement across and within nurse-parent relationships encompassed in the '*creating a space between myself and parents*' and '*managed empathy and emotional self-regulation*' sub-themes of *Purposeful positioning*, appeared to help the participants achieve an overall balance between emotional under and over-involvement. This helped them to remain in the 'zone of helpfulness' and within the confines of a professional therapeutic relationship, as illustrated in Figure 6.1. Although I would suggest that Les seemed to be on the outer reaches of the zone of helpfulness straying towards under-involvement. However, although Les had worked at the hospice for just 4 years she had worked in other areas which sometimes involved CPC and long-term relationships for a decade prior to this. Therefore, as identified by Pearson (2013) (discussed in the literature review) she may have been suppressing feelings and disengaging from relationships with parents as a protective measure.

**Figure 6.1: The continuum of professional behaviour for emotional involvement**



Adapted from NCSBN (2018)

### **6.3.2. Balancing personability and professionalism through the lens of EI**

As highlighted in my summary of this theme in Chapter 5.4.4, building and maintaining relationships which were in keeping with the philosophy and atmosphere of the hospice whilst maintaining professional boundaries was complex. The *Balancing personability and professionalism* sub-themes arose from the two main issues identified, which were '*managed self-disclosure*' and '*I am a friendly professional; I am not their friend*'; hence the challenge to relational professional boundaries. Jo's words below (referring to short break and day care) highlight the more personal yet professional nature of the relationship.

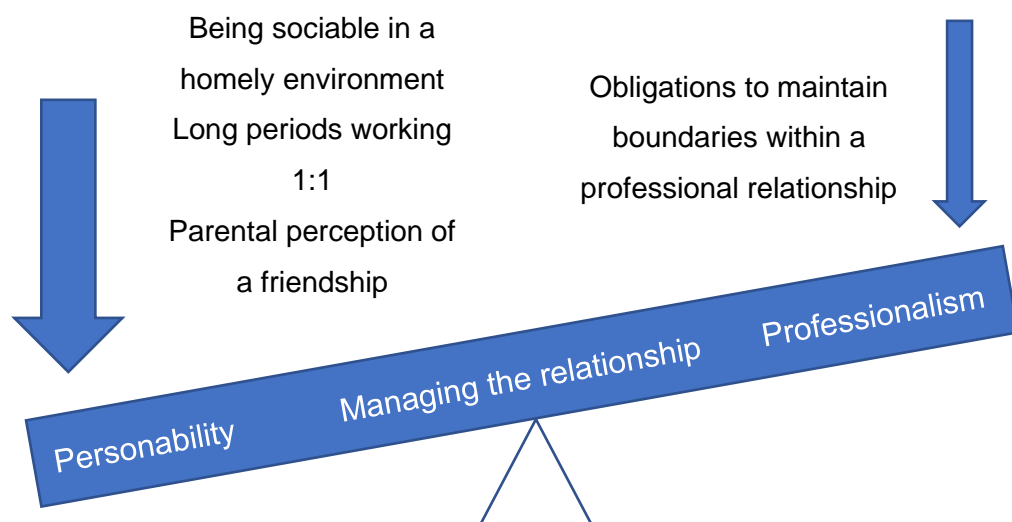
*I suppose because you are, you're involved in less medical time together, relationships do become a bit more personal but in a professional way, if that makes sense. [Jo]*

So, the personal ‘face’ of the nurse appeared to be at the forefront whilst the nurse as a professional in the formal and clinical sense is present but a somewhat ‘secondary’ part of the relationship.

The acknowledgement that nurse-parent relationships were different from other clinical areas fits with the work of Maunder (2013) (featured in Chapter 2), who identified that CPC hospice and community nurses adopted informal, non-traditional professional personas as a means of forging relationships with families.

Figure 6.2 illustrates the factors identified by the participants which pose a challenge to managing their interpersonal interactions with parents. This is represented by two sides of a scale to show the influences on the ‘personability’ side compared to those on the ‘professionalism’ side. Thus, demonstrating the imbalance. This does simplify the situation because personability and professionalism are not mutually exclusive. However, I feel the diagram helps to illuminate and summarise my interpretation of the participant accounts.

**Figure 6.2: The imbalance between influencing factors in nurse-parent relationships**



The *Balancing personability and professionalism* theme is congruent with the literature review in terms of the findings of Erikson and Davies (2017) who identified the tension between ‘connecting personally and behaving

professionally' (p.45) and how successfully managing these two things simultaneously deflected threats to professional boundaries and integrity.

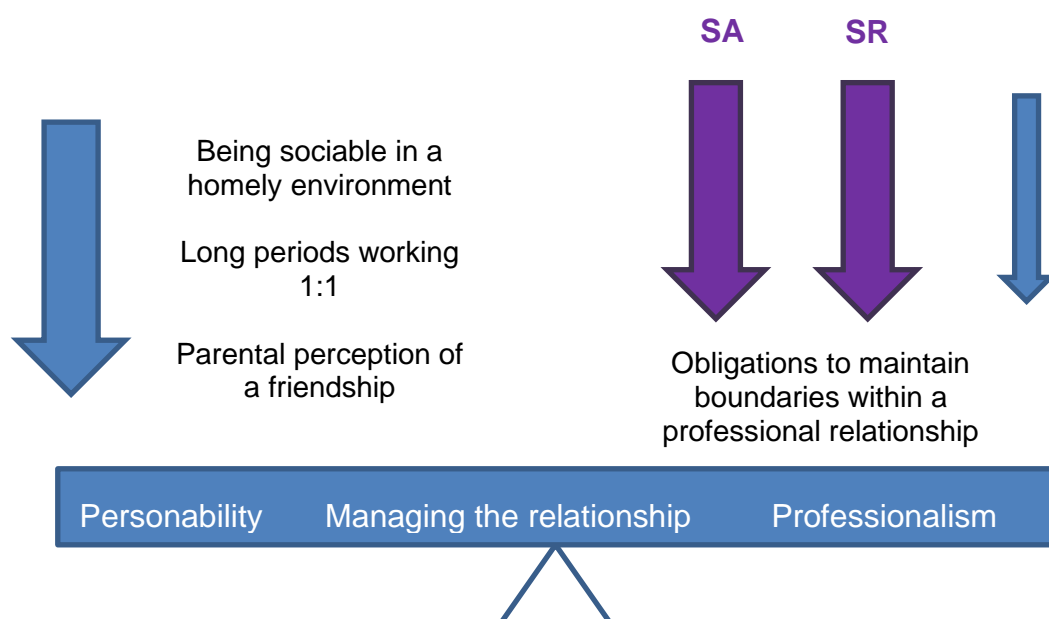
Mesmer-Magnus et al. (2008) identified that those with high levels of EI were unlikely to engage in counterproductive or unethical workplace behaviours and, indeed, my study participants clearly identified the need to address the factors influencing this imbalance. Their accounts suggested the use of self-awareness and active self-regulation. For example, although Alex, Patrick, Ashley, Jo and Chris disclosed personal information to parents their approaches were varied, highly moderated and adapted to the parent and situation, whilst being mindful of professional boundaries.

*I've always been quite aware of... the temptation to share sort of significant life events... you have to have a professional boundary. So there have to be lines that you are not prepared to cross. [Patrick]*

*I think you just have to, to work in a hospice you just have to be able to have that barrier and that professionalism. [Jo]*

Figure 6.3. offers a simple illustration of the equipoise achieved by using self-awareness and self-regulation.

**Figure 6.3: Maintaining a balance in nurse-parent relationships using Emotional Intelligence** (Key: **SR** = Self-regulation, **SA** = Self-Awareness)



In contrast to the other participants, Les' self-regulation was less flexible because she did not reveal any personal information to parents, citing professional reasons for this as well as her propensity to fiercely guard her privacy.

This difference in approaches is important in terms of achieving the balance discussed here. Davis and Nichols (2016) identified the potential for negative consequences if EI constructs were not equally developed. So, practitioners who have under-developed self-awareness and self-regulation may not be able to achieve balance, thus leading to difficulties in managing their relationships with parents, which may involve relational professional boundary breaches. Likewise, overdeveloped self-regulation may have consequences. For example, although Les was happy with the way she managed her interactions with families she did acknowledge that her stringent approaches to personal disclosure and keeping families at arms' length suggested a lack of other constructs of EI such as social engagement and empathy:

*I'm not a ridiculously anti-social person that I might be coming across as*

*I do sound incredibly cold don't I' [Les]*

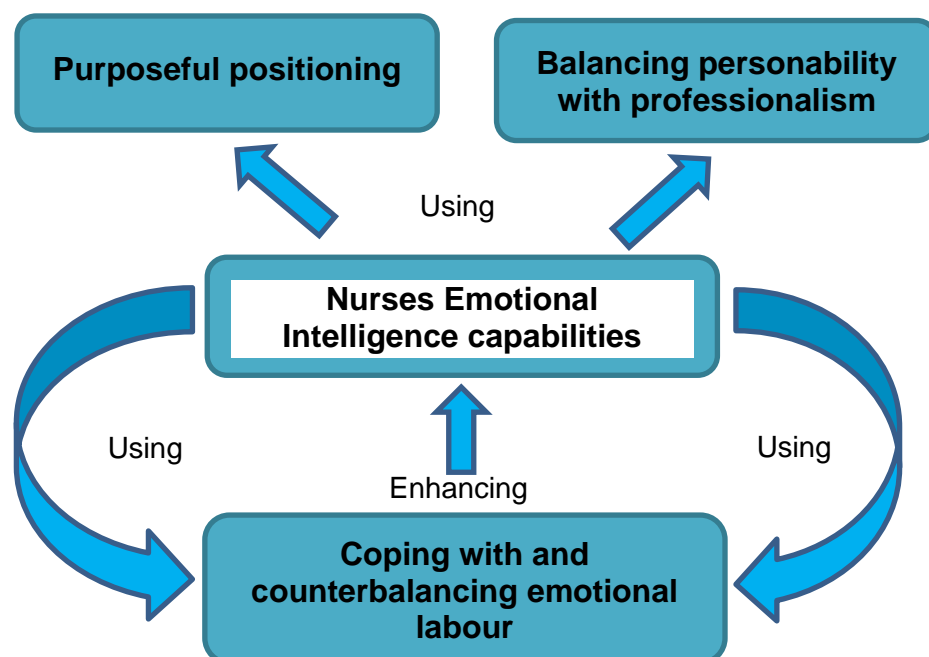
Although this highly regulated approach means that Les is very unlikely to stray into unprofessional territory it may negatively affect her engagement with other aspects of CH work; particularly those within the *Coping with and counterbalancing emotional labour* theme. Indeed, she did not mention peer support or job satisfaction.

### **6.3.3. Coping with and counterbalancing emotional labour through the lens of EI**

The *Coping with and counterbalancing emotional labour* theme encompassed hospice activities and features which ameliorated the effects of emotional labour and helped participants cope. This is in keeping with the findings of Kase et al. (2018) from the literature review. In the case of my findings these coping mechanisms or counterbalances were noted to be more abundant than the negative aspects of the role.

Initially the sub-themes of '*Coping with and counterbalancing emotional labour*' (*job satisfaction, positivity and fun* and *extraordinary peer support*) appeared to be unrelated to EI and I set them aside whilst I explored the theory and relevant literature. However, whilst considering if EI was a suitable lens through which to explore '*Purposeful positioning*' and '*Balancing personability and professionalism*' I encountered literature and formulated ideas about how it may also apply to the '*Coping with and counterbalancing emotional labour*' sub-themes, i.e. CH features which appeared to exist and benefit the participants regardless of whether they used EI constructs or not. The deeper I delved into EI research, in a range of contexts, the more the possibility of a link with EI was revealed. What I discovered was that individuals would need EI constructs to engage with *positivity and fun* and *extraordinary peer support* or experience *job satisfaction*. There was also literature to suggest that these features may also enhance EI constructs. If this is so, then these activities may have not only acted as counterbalances to emotional labour during and after the event but also positively contributed to the participants' ability to manage the emotional and relational aspects of their role in the future. Figure 6.4 Illustrates my thoughts on this.

**Figure 6.4: Using and enhancing Emotional Intelligence in CHs**





Unlike previous sections, this part of the discussion will be split into sub-themes. I feel they merit individual exploration because the participants were clear that the level at which they experienced these elements of their work were specific to the CH. Moreover, had they not existed their ability to cope would be severely compromised.

### **6.3.3.a. Job satisfaction**

Literature from other disciplines (Ealias and George 2012; Pau and Sabri 2015; Lee 2018; Suleman et al. 2020) and nursing (Güleryüz et al. 2008; Yarzan-Parast et al. 2015; Kassim et al. 2016; Tagoe and Quarshie 2017) has identified a correlation between job satisfaction and EI, in that those who possess EI, particularly emotional self-awareness and self-regulation, tend to be more satisfied with their jobs. It is suggested that this is because they are more likely to have skills which enable them to overcome difficulties and work to a high standard. Therefore, it may be that my participants were satisfied with their role because they possessed EI. However, they emphasised that, in addition to the feeling of doing a job well, it was the nature of the work, i.e., being passionate about doing something worthwhile, that added an extra dimension to their feelings of satisfaction.

*So for me it was just that spending time with the child and the family and just making an awful time as good as it possibly can be and I suppose to provide the nursing care that I want to give. [Jo]*

*... the quality of care, the opportunity to help the family to the best of your abilities ... that is a good thing. [Patrick]*

Whilst, as identified in the literature review, it would be likely that the participants would be motivated by some intrinsic factor to commence a hospice nursing role in the first instance (Hill-Jones 2008; Katz 2016), the study participants had been in post for between 4 and 32 years. So either these motivators had sustained them (Newman 2014) and/or other intrinsic factors had come into play. Therefore, the satisfaction of doing a worthwhile role was likely to contribute to internal motivation accumulatively, thus feeding back into the development of the EI construct of intrinsic motivation (Newman 2014), particularly commitment to the organisation and its aims (Güleryüz et al. 2008).

### 6.3.3.b. Positivity and fun

The notion of having fun within an environment where all the children are predicted to die before they reach adulthood is alien to most people and probably the most difficult aspect of CHs to explain.

*I think it's hard to explain isn't it ... to people who have never worked or had anything to do with a children's hospice that even when a child is dying, it's very sad but we will always try, as long as that's what the family are wanting, we'll always try to just carry on making memories and having fun ...' [Jo]*

Goleman (2020) states that the ability to celebrate the positive and specifically to find a positive in a negative is a key feature of emotionally intelligent people. Engaging in positive and fun experiences can also enhance an individuals' ability to cope with adversity (Newman 2014). Therefore, the participants of this study were likely to have not only benefitted from *positivity and fun* as a means of counteracting and coping with emotional labour but also increasing their intrinsic motivation. This is demonstrated in Alex's words below:

*I'm driven by making [memories], by that kind of thing ... You know sometimes it might be the way that someone looks at you or, or a mad event that you've done, dyed somebody's hair pink or something. Crazy things that you think, gosh how many people in the world get the chance to do that in their job ... So you've provided the child and the family with a memory but actually you've also done something that impacts on your own life in a lot of ways ... [Alex]*

This is congruent with the idea that finding meaning in nursing practice can offset negative effects (Boyle and Bush, 2018) and the notion of post-traumatic growth identified in the literature review (Beaune et al. 2018). So, although participants may have started with a motivation to help families maximise the time they have together, witnessing the benefits of this for the family and feeling the benefit for themselves is likely to increase their passion and intrinsic motivation for the work.

Ashley acknowledged the importance of fun and positivity at the hospice and how the existence of more good days than bad allowed her to continue in the role.

*I mean you have to have more good days than bad days haven't you, unless you wouldn't be able to do it. [Ashley]*

This suggests that, if there were more bad days than good, not only might it impact on coping but perhaps the individuals' intrinsic motivation would be compromised, so if the 'bad' days reduced optimism then perhaps the ability to persevere would be affected. So, even for those who started with high levels of EI, an absence of positivity in the workplace may reduce their intrinsic motivators (Goleman 2020).

### **6.3.3.c. Extraordinary peer support**

Whilst the apparent possession of EI, specifically social skills, may have enabled the participants to maintain good relationships with their peers, this would be true wherever they worked. Nevertheless, having formed these relationships, the focus on peer support at the hospice was likely to have been instrumental in nurturing these skills further.

Les was the only participant that did not mention peer support, referring to more formal mechanisms or external sources when asked about support. As identified earlier her self-regulation was stringent so perhaps this was out of balance with other EI constructs and therefore presented a psychological barrier to engaging in this activity. However, as identified in the literature review (Pearson 2013), nurses who have worked with families of life-threatened or life-limited children over long periods of time, as Les had, often disengage with colleagues (as well as service users) as a protective measure.

Peer support as a cultivator of EI has been researched (Saud et al. 2016). Their study found that peer support promoted cohesion which resulted in confidence, trust, respect and empathy among the group, subsequently developing and enhancing EI skills. Simply put, an individual possesses Social Skills which enables them to form relationships with peers and subsequently the support obtained enables enhancement of EI skills. I was

unable to locate any research that was specific to peer support and the development of EI overall in nursing. Nevertheless, in terms of the stories my participants told me I would suggest that this may be possible in relation to individual EI constructs. Indeed Sadri (2012) suggests that development of EI skills as separate entities is effective and worthwhile. My participants described ad hoc and informal peer support as a vehicle through which they could connect with and explore their emotions in a very open way.

*I believe that it's really only your peers who understand... they are the only ones who understand the situation, what it is ... We often do it as well in a safe space where we just blurt out what we want to blurt out ...it's kept confidential.'* [Chris]

*You just need to get it off your chest.... You know let them [colleagues] have a rant, ... just get it off their chest, because sometimes that's all you need.* [Patrick]

This type of emotional unburdening has been shown to promote self-reflection (Duke et al. 2015) and consequently the EI constructs of self-awareness and self-regulation skills. Further the part individuals play in helping others via peer support has been shown to increase the self-awareness EI construct (Schwartz and Sendor 1999).

It could also be argued that the mutual understanding of work demands, between peers (outlined in the extract from Chris' transcript above) may not only require empathy but develop empathy, as demonstrated in other mutual peer support systems, particularly for emotive situations which challenge an individuals' mental well-being (Collins 2019). Finally, giving peer support in the hospice situation would certainly require optimism and perseverance in the face of adversity. Moreover, by benefitting from this as a coping mechanism and using it as a learning opportunity, the recipient's levels of optimism and perseverance may also increase (Newman 2014); thus, enhancing their skills in the EI intrinsic motivation construct.

#### **6.3.4. Exploring the study themes through the lens of EI: Summary**

Exploring the study findings through the lens of EI helped me make sense of the participants approaches to emotional and relational management from the perspective of the variation across participants (e.g. high levels of self-

regulation through to a more fluid approach). It also helped me to gain an understanding of the traits which may be used (singularly or in combination) to enable individuals to be flexible in a range of situations, whilst remaining within the bounds of a professional therapeutic relationship and safeguarding their own emotional well-being.

Although I had not originally intended to explore the *Coping with and Counterbalancing emotional labour* theme sub-themes of *job satisfaction, positivity and fun, extraordinary peer support* via EI, this has revealed a possibility that these features not only ameliorate emotional labour during and after the event, but they may contribute to its management prospectively by enhancing some elements of EI such as intrinsic motivation and empathy. This requires further investigation but if this proved to be the case it suggests that the very nature of CH work naturally nurtures practitioners that are better equipped to cope with its demands. Something of a self-perpetuating, self-sustaining capability cycle.

It is unlikely that practitioners will constantly remain at the centre of the continuum of emotional over and under involvement (Figure 6.1). They will move to back and forth along it. Likewise, the balance between personability and professionalism (Figures 6.2 and 6.3) will alter depending on situations and their influence on individuals, as well as how a nurse may be feeling on any given day. Moreover, counterbalances to emotional labour may, at times, be ineffective. However, both the study findings as a stand-alone entity and their exploration through the lens of EI contribute to understanding how CH nurses manage emotional labour and maintain professional integrity in their relationships with parents. Thus, meeting the aims of the research study outlined in Chapter 3 and Box 6.1.

#### **6.4. Application of EI and the findings to CH and CPC**

The exploration of the study findings via EI provides not only a possible explanation for how the participants met the families' needs, whilst protecting their own well-being, but also a vehicle for suggesting how this knowledge and understanding may be used. Sections 6.4.1 - 6.4.2.c present proposals for how EI theory and the findings of my study could be used by CHs

nationally and internationally to inform recruitment and retention, practice and staff development. There are also suggestions for formal pre and post registration education which could be used in CPC and nursing more widely. The suggestions relate to the Macro, Meso and Micro (Pilgrim and Rogers, 1999) levels appropriate to that area. These are shown in Table 6.4 below. However, it should be noted that the global impact/reach of some of these suggestions would be limited in some countries because palliative care provision is influenced by the presence (or absence) of the following four factors: policy, education, drug availability and implementation infrastructure (WPCA and WHO 2020). Furthermore, many developing countries do not have the resources to provide CPC or, indeed, recognise it as a speciality (Downing et al. 2018).

<b>Table 6.4: Target areas for Macro, Meso and Micro level Recommendations</b>			
	Macro (Strategic)	Meso (Organisational)	Micro (Operational)
Recruitment and Retention	CHs internationally	CHs throughout the UK	Individual CHs
Formal Nurse Education	International HEIs delivering pre and post registration nursing courses	UK HEIs delivering pre and post registration nursing courses	CHs developing formal (possibly HEI accredited) post registration courses
Practice	International or national influencers of CH practice (e.g. ICPCN, EAPC, TfSLs, NMC, RCN)	Individual hospices	Individual practitioners
Staff Development	National guidance (e.g. TfSLs)	Individual hospices	Individual practitioners

#### **6.4.1. Recruitment and Retention**

The suggestion that screening for EI competencies in pre-registration nursing candidates and for qualified nurses has been made in the past (Kooker et al. 2007). My study findings indicate that this may be particularly desirable in the CH setting where emotional and relational management demands on registered nurses, nursing associates and HCSWs are high.

Undergraduate nursing recruitment involves value-based questions and assessments which link to EI (DH 2013) and this approach to recruiting qualified nurses would certainly enable hospice managers to explore applicants' intrinsic motivations at interview. However, given the complexity of hospice care, and the self-reported emotionally intelligent practice outlined by the study participants, I would suggest that a more comprehensive exploration of a candidate's EI would be beneficial. Although recruitment of children's nurses to hospices has been highlighted as problematic and one would not want to place further barriers in the way of this, retention is also an issue (TfSL 2019). Therefore, recruiting nurses who already have a level of EI could improve retention and reduce difficulties caused by individuals being ill-equipped to deal with the unique service provision of CHs. In fact, possession of EI has been shown to be a factor in retention of nurses and positively correlated to longevity of career (Codier et al. 2009). More specifically compassion fatigue, which was identified as an issue in CPC within the literature review (Maytum et al. 2004; Rushton and Ballard 2011; Pearson 2013) is a factor which influences staff turnover in adult oncology nursing (Wells-English et al. 2019) and can be avoided or reduced if health practitioners possess EI traits (Zeidner et al. 2013; Kabunga et al. 2020).

Recruitment of staff who possess EI could be achieved by using a measure such as the Trait Emotional Intelligence Questionnaire (TEIQue) (Petrides 2009). This self-report tool provides an indicator of behaviours in a variety of situations (O'Connor et al. 2019) and could be used as part of the application or interview process. In terms of external recruitment for higher level positions or considering internal promotions, a measure of EI specifically developed for leadership could be used. For example, the Emotional and Social Competence Inventory (ESCI) (Boyatzis et al. 2017). Nevertheless, even validated tools such as these will have flaws and, given the criticisms of EI measurement, the results of such assessments should be considered alongside equality of opportunity, professional judgement and other factors pertinent to the role such as experience and competence.

The findings from my study could also be used to underpin recruitment campaigns. Research is likely to be regarded as more robust evidence of the

benefits of working in CH when compared to films such as 'You can be that nurse' (TfSL 2016c) recorded specifically for recruitment purposes; particularly as the study was inductive rather than deductive, i.e. I had not set out to identify *positivity and fun, job satisfaction* or *extraordinary peer support*, only what sustained CH nurses in their role.

#### **6.4.2. Education, Practice and Staff Development**

EI research literature suggests that EI traits can be developed directly through formal mechanisms such as training. There is also a possibility that hospice features such as *job satisfaction, positivity and fun* and *extraordinary peer support* may enhance EI. The following sections discuss EI development through formal nurse education, practice and staff development.

##### **6.4.2.a. Formal Nurse Education** <sup>15</sup>

As mentioned in the literature review conclusion (Section 2.8), the findings of this study may contribute to pre and post registration nurse education at all levels, including nursing associates, nationally and internationally.

Exploration of my findings alongside EI literature has demonstrated that EI traits improve nurses' performance and ability to cope with the emotional demands of their role. The link between EI and emotional labour has already been recommended for inclusion in nurse education (McQueen 2004) and I would concur. Specifically, my findings in relation to managed empathy are linked with the recommendations of Kang and Choi (2020), who stated that EI and development of specific types of empathy should be part of nursing curricula to improve hospice and palliative care. However, Wilson (2014) demonstrated that nursing staff may not understand what EI is. So pre and post registration programmes need to clarify the concept of EI before attempting skills development.

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<sup>15</sup> These are overarching statements about the application of the findings to formal nurse education. The impact of the study on my own practice as a nurse educator is outlined in Section 6.9.



The importance of EI is recognised in a number of educational and competency standards. The European Association for Palliative Care (EAPC 2013) advocated a more relationship-centred approach to the education of the CPC workforce and many of their competencies allude to EI. Some specifically identify EI constructs such as self-awareness. The RCN (2018) competencies specifically mention EI in relation to child/family interactions and staff well-being. The CPCET (2020) Framework recognises elements of the nurse-patient/family relationship which were identified in the study and which, in the case of my participants, appear to have been managed using EI traits, e.g. professional boundaries and therapeutic relationships, managing emotional labour and maintaining well-being. The recent advent of the Education Standard Framework (CPCET, 2020) is encouraging because if education providers choose to develop programmes based on this then some of the issues raised by my participants can be incorporated into teaching and learning. If providers combine this with the RCN (2018) competencies, particularly for programmes which have an assessed practice element then this is likely to produce a programme which could nurture EI alongside practical skills, e.g. via an assessed reflective journal which focuses on the emotional and relational aspects of the role. For staff working in CHs (and possibly other CPC areas) the framework which I outline in Section 6.7 could be part of this reflective journal.

CHs who employ skilled and knowledgeable educationalists and/or have strong links with Higher Education Institutions (HEIs) could use the RCN (2018) and CPCET (2020) documents to develop in-house (possibly HEI accredited) education programmes. These could focus on one or a range of the EI linked standards/competencies therein.

#### **6.4.2.b. Practice**

Professional boundaries were referred to by the participants in many guises, i.e. emotional involvement, emotional behaviours and personal disclosure. So, it seems that the phrase 'professional boundaries' not only means different things to different people but also different things to the same person, depending on context. Although the subtle differences may be suitable for discussion within a research thesis and for dissemination to

academic audiences, these may be lost when trying to translate them for a wider pre or post registration audience. Therefore, although having undertaken this study, I would be reluctant to label all the issues raised as 'professional boundaries', it may be necessary to do so to locate the discussion in a 'place' with which the audience are familiar, particularly as this has been recognised as a difficult area to teach (Cargill 2014; Buder and Fringer 2016). Having said that, my findings may make it easier to explain the subtleties and nuances of navigating the emotional and relational elements of long-term relationships with parents. Furthermore, although the NMC (2018) refers to professional boundaries they do not provide specific guidance in the same way as professional regulators in other countries. For example the USA NCSSN (2018) offers a comprehensive guide to professional boundaries. In light of my findings in relation to the blurring of professional boundaries, perhaps more comprehensive and explicit guidance from NMC or RCN is required, particularly in relation to personal disclosure where there was the greatest range of approaches. This is not to say that there can ever be an absolute directive, as my own and other research from the review demonstrates that this is not a 'black and white' area (Papadatou 1991; Maytum et al. 2004; Erikson and Davies 2017) but additional guidance may be useful. Guidance which is specific to CHs may also be warranted due to the unique nature of the speciality and environment.

The final element of practice I would like to highlight is the culture of *extraordinary peer support* in the CHs in my study. Five of the six participants cited this as a major contributor to helping them cope with the demands of the role and was highly valued. The participants also revealed that it was informal peer-support, rather than formal mechanisms provided by the organisation, that was most helpful. Patrick highlighted that formal support such as clinical supervision could sometimes feel disciplinary rather than supportive. This contrasts with the CH study of rewards and challenges by Taylor and Aldridge (2017) which highlighted the value of formally organised clinical reflection. However, this was an MDT study where nurses were grouped with doctors and the number of allied health professional and other participants made up 71% of the sample. Therefore, the findings could not confidently be applied to either doctors or nurses. So, I would strongly

recommend that hospices continue to foster a culture of informal peer support; both in light of my study findings and because previous work (Mann 2005) has highlighted the need for managers to either reduce the number of events requiring emotional labour (difficult in CHs) or moderate the negative consequences of emotional labour (possible through peer support). In addition to being a means of coping with emotional labour, peer support has been found to positively influence a range of professional behaviours Deshpande and Joseph (2009).

In the same way I have suggested UK guidelines for professional boundaries, I would recommend that emotional labour in CPC be given similar attention. Emotional well-being does feature in some CPC practice guides (TfSL 2018a) but this is very brief information about self-care activities. It would be unhelpful to suggest strategies for management of emotional labour without evidence that is specific to CPC. So dissemination of my findings and their application to EI could be useful information for practitioners and play a role in underpinning staff development activities (outlined below). Dissemination of resources developed for CPC practice (such as the framework outlined later) could be achieved via a national CPC network such as TfSL (subject to author acknowledgement and any other copyright regulations). TfSL have a nationwide reach and are a major practice influencer for CPC provision.

#### **6.4.2.c. Staff Development**

A culture of staff development in CHs is mandated (CQC, 2020) and well embedded via various approaches, including dedicated professional development days/weeks which are underpinned by education strategies (Billings and Jenkins 2011; Malcolm and McGirr 2018). Such strategies acknowledge the emotional and relational demands of CH work and recommend that provision is made for these elements of the role alongside clinical competence training. The findings of my study and my proposal that this relates to emotionally intelligent practice could be incorporated into staff development activities.

Goleman (2020) claims that individuals are born with some level of EI, the extent of which determines their potential to develop this further. He also

stresses that the emotional competencies within each construct of EI are not innate talents but can be learned to improve job performance. There is evidence that it is possible to increase an individual's EI levels through training (Slaski and Cartwright 2003; Nelis, et al. 2009; Codier et al. 2013) with job satisfaction being increased as a result (Yarzan-Parast et al. 2015). Codier et al. (2013) studied EI development in adult oncology nurses via training and found that increased levels of EI improved coping mechanisms in stressful or emotive environments.

Development of existing staff should be based on enhancing current skills and targeting areas that require improvement. A baseline measurement could be taken by observing abilities using the Mayer-Salovey-Caruso Emotional Intelligence Test (MSCEIT) (Mayer et al. 2002) and a bespoke training plan developed to address deficits. The same tool could be used to measure post training EI levels within the targeted constructs. This is an approach used in studies by Groves et al. (2008) and Clarke (2010) with the latter using the tool in the targeted manner outlined above. This was based on his detailed critique of EI training (Clarke 2006) in which he identified that work based, context specific learning was preferable to standard EI training programmes. Clarke's (2006) ideas would certainly fit with what I propose above in relation to enhancing EI skills for nurses currently working within the specialised, highly skilled and emotive hospice environment. Moreover, it may be pertinent to consider Sadri's (2012) work which suggests that development of EI skills should be targeted at individual constructs and characteristics rather than education and training which addresses EI as a whole.

When CH staff are completing NMC revalidation they could use the proposed EI framework in their reflections on interactions with colleagues or parents. This would add another layer to revalidation reflections and raise awareness of EI traits, how they apply to CH nursing and areas for improvement. This could also feed into self-assessment within the PDR and provide a rationale for accessing external training opportunities. On a broader level children's nurses working in other areas or, indeed, nurses in all fields could use EI constructs to underpin reflection. As practitioners we often reflect on our

actions and their consequences but may not necessarily explore those actions at a visceral level. EI would provide a framework for this type of reflection.

## **6.5 Impact of Covid 19**

It would be remiss of me not to acknowledge what the pandemic has meant for nurses working in CHs and apply my findings to this. At the start of the pandemic CHs had to reconfigure services to protect the vulnerable children in their care (most of whom were shielding). Approaches varied; where CHs remained open, planned respite visits and day care ceased, concentrating efforts on EoL care and emergency respite. So many of the usual fun activities which my participants identified as a counterbalance to the emotional aspects of care would be absent. Moreover, reduced service provision would mean that fewer staff would be on site thus reducing interactions and opportunities for the ad hoc, informal, face to face peer support which my participants valued and identified as another counterbalance to the demands of their role. The other element of counterbalance (*job satisfaction*) would be less affected as the opportunity to continue with a worthwhile role and deliver high quality care would still be present, but satisfaction may have been reduced by the knowledge that many families would be without valuable planned respite. The long-term relationship that nurses have with parents and knowledge of their personal circumstances is likely to have meant that the inability to provide short-break and day care was distressing.

Working with vulnerable children during a pandemic requires high levels of PPE and this would have inevitably affected communication and interactions with families and colleagues. Therefore, the social skills normally used by nurses would have to be adapted. Nevertheless, there is only so much that can be done to overcome the barrier of gowns and masks/visors. So, interactions would be pared down to the minimum, making what was previously highly interactive and often fun somewhat functional. It could be argued that this removed some of the challenges to balancing the relationship which were identified by my participants. However, interactions which are solely functional, focused on emergency needs and EoL, without

the variety that CH nursing usually provides, may have also negatively impact nurses' mental health.

Lockdowns and ongoing restrictions have impacted on charities' ability to fundraise through usual avenues. The subsequent deficit in income is very likely to affect some service provision which may frustrate staff and reduce job satisfaction. Furthermore, there will be less money available for training and staff development activities such as those I have suggested. Job security may also be affected if CHs need to reduce their staff budget.

The mental health impact of the pandemic has been widespread regardless of an individuals' employment or personal circumstances (Health Foundation 2020). This may have reduced CHs nurses' ability to cope with the emotional demands of their role, particularly if the usual counterbalances are absent or altered, as outlined above. The mental health impact of the pandemic is likely to mean that emotional reserves and coping strategies are reduced (Ogueji et al. 2021) so the ability to create the psychological space described by my participants and/ or manage empathy and self-regulation may be affected.

## **6.6. Limitations of the study**

Research design limitations were acknowledged in Chapter 3. However, having now presented the analysis and discussion it is important to revisit this to add further comment based on the experience of undertaking the research.

The decision about which relationship or shift to include in the diary was made by the participants. They may have selected situations which would show them in a favourable light. Nevertheless, this is true of many data collection methods and approaches.

In terms of long-term nurse-parent relationships within the CH, my findings are limited to short break and day care interactions since this is what I asked the participants to focus on. Therefore, these findings cannot be applied to CH work overall as they do not relate to EoL situations. Furthermore, as the

research was undertaken in the UK it may not be wholly transferrable to other countries due to cultural differences.

Data collection methods did not involve face to face researcher-participant interaction, negating body language cues. On reflection I could have used video calling for interviews but, at that time, I felt this would be too demanding since I was already asking participants to record audio diaries on mobile phones and transmit them electronically. Since the advent of Covid 19 practitioners have become more familiar with various technologies so, should I repeat this study, I would perhaps use video calling for the interviews.

The nature of the data collection method for the audio diaries may have also limited the breadth of the sample as only those who felt able to record on their mobile phone and transmit via WhatsApp or record on a Dictaphone could take part.

Although I asked the participants to focus on emotional and relational aspects of their interactions with parents, since they were caring for the child alongside this, it was inevitable that their feelings about the child would be embroiled in their accounts. It would be impossible to isolate the nurse-parent relationship. Indeed, the relationship with the whole family would be more than the sum of its parts. Moreover, all families referred to by the participants were heterosexual couples so the findings may not apply to nurse-parent relationships with same sex couples.

Although the data were collected from five different hospices, three of the participants worked for the same hospice group (with two working at the same hospice). So, the findings may have been influenced by this.

### **6.7. An EI framework for CH nursing practice**

Having identified gaps in the fit between existing EI models and nursing-client relationships (particularly for my findings) in Section 6.2.3; I present below a suggested framework for managing relationships with families in the CH setting. This draws on relevant elements of current models and combines these with the findings of my study. Although it could be argued that this is very 'niche', Zeidner et al. (2004) state that EI models should be based on

theory and empirical research which is relevant to a particular occupational context. The intention of the framework is to highlight that navigating nurse - parent relationships in the CH is challenging and provide guidance which is based on existing evidence (from the literature review and EI models) and this thesis. Although it would be useful for all CH staff, it would be particularly useful for new recruits and nursing students as it would 'set the scene' and provide a guide for managing relationships with parents from the start of the relationship. There are, of course, other theories which could be applied to my findings and EI may not appeal to all. Furthermore, the label of being emotionally intelligent, or not, may be divisive. However, it could be a useful tool for individual or group reflection and/or a tool to underpin evidence of good practice at a PDR or at NMC revalidation. The style of the framework may be too 'wordy' and cluttered for some but enlarging to A3 size may help. Different colour backgrounds may also be necessary for staff with some types of dyslexia and a more pictorial presentation with footnotes may be a simpler way of conveying the messages in the framework.

It could also be argued that the concept of EI is only recognised in developed countries and therefore the framework would not be suitable for implementation on a wholly international basis.



Table 6.5: Using EI to <u>N</u> avigate <u>R</u> elationships in <u>C</u> hildren's <u>H</u> ospices: A framework for <u>n</u> urses (ENRiCHn).					
Relationships with colleagues (based on Goleman 1998)				Relationships with families (based on study findings)	
Characteristics		Construct		Children's Hospice specific considerations (in addition to Goleman 1998)	
the ability to know one's emotions, strengths, weaknesses, drives, values and goals and recognise their impact on others while using gut feelings to guide decisions.	Personal (intrapersonal) competency	Self-Awareness		Be aware that relationships with families in children's hospices have a different dynamic to elsewhere. This is likely to affect you emotionally and influence your interactions. Sharing thoughts with peers and getting their feedback will help you develop self-awareness <sup>2</sup>	Personal
self-control, controlling or redirecting one's disruptive emotions and impulses, respond rather than react, think before acting, comfortable with ambiguity and ability to adapt to changing circumstances, trustworthiness and integrity.		Self-Regulation		Create psychological space between yourself and families in and out of work. Use appropriate types of empathy <sup>1</sup> to regulate emotional involvement with families. Carefully manage self-disclosure. Experienced peers can advise and help you <sup>3</sup>	
a passion to work for reasons beyond money or status, an awareness of personal motivators, optimism and perseverance in the face of adversity, organisational commitment.		Intrinsic motivation		The opportunity to deliver good care, spend time with families and help them make the most of the time they have together is motivating and satisfying. Recognise the things that motivate you and enjoy them. Positive (memory making) and fun activities can increase your motivation and help to counteract the emotional demands of the role <sup>2 &amp; 3</sup>	
ability to understand other people's emotions and reactions (only possible if self-awareness is achieved) considering other people's feelings especially when making decisions.	Social (interpersonal) competency	Empathy	Managed Empathy	You need to understand other people's and your own emotions and reactions. Empathise but do this carefully by using appropriate types of empathy. <sup>1</sup> You need to be self-aware to achieve this. <sup>2 &amp; 3</sup>	Personal & Social
managing relationships to get along with others, communication skills, finding common ground with others, building a rapport, conflict management.		Social skills		The unique hospice environment will influence your interactions with families. Engage with them on a social level but be mindful of your role and professional responsibilities, manage self-disclosure carefully, be a friendly professional not a friend. Experienced peers can support you with this. <sup>2 &amp; 3</sup>	Social
1.Types of empathy appropriate to a professional role: Cognitive (see a situation and the associated feelings from the other persons perspective) and Compassionate (understand, care and help) identified as the 'ideal' (Goleman et al. 2017). Inappropriate in a professional role: Emotional empathy (physically feeling alongside the other person, almost as if their emotions were contagious). 2. Recognition: Who I am. 3. Regulation: What I do (Cherniss & Goleman 2001)					

## 6.8. Unique contribution

My study is unique because unlike other studies which explore nurse-parent relationships in CPC (Maunder 2013; Erikson and Davies 2017) it was carried out exclusively in the independent sector with CH nurses. Therefore, it offers an insider perspective on aspects of CH work. Maunder (2013) and Erikson and Davies (2017) identified some similar concepts in terms of the strategies for managing the emotional burden and balancing the personal and professional. However, these are not discussed through the lens of EI.

Most advice in relation to managing the emotional aspects of CH work refers to self-care activities. The findings of this study, and their exploration through the lens of EI, provides an evidence base for an alternative which is proactive and developmental.

Data collection for this study occurred between March 2019 and January 2020 and the methods selected at the start of the project were driven by my wish for timely recording of audio diaries and to undertake interviews as soon as possible after audio diary submission. At the time of data collection, although other studies had used audio diaries these were usually via a Dictaphone with postal transmission. Therefore, the use of mobile phones and WhatsApp as a means of transmission were novel. More recently and certainly since the event of Covid 19 there have been publications which refer to the use of mobile phones to record data and WhatsApp as a means of transmission (Kaufman and Peil 2020; Singer et al. 2020). I intend to contribute to the knowledge base on using this technology by writing an article outlining how they were used in my study.

Synthesising my findings with EI theory and research has enabled me to develop an EI framework for relationship management in CHs. This framework combines colleague and patient/client relationships making it more suitable for nursing than the colleague focused, business orientated models developed by Goleman (1998) and Cherniss and Goleman (2001). By developing ENRiCHn (Using EI to Navigate Relationships in Children's Hospices: a framework for nurses) I have repurposed an established theory. In using EI as the basis for the framework I provide an alternative to others

used to underpin support and development in emotive care environments e.g. resilience (Hospice UK 2015). The framework is CH specific but individual aspects could be adapted for other areas of nursing practice where long-term nurse-parent relationships exist.

### **6.9. Impact of undertaking the Professional Doctorate on my practice**

From a personal perspective, as an educator of pre and post registration nursing students, there are many ways in which conducting this research study will enhance my contribution to my field of 'practice'. Undertaking the taught part of the doctorate and conducting the research has taught me what it means to be a researcher. Undoubtedly I still have much to learn but the experience will enable me to better explain the process to my students and help them understand the benefits and challenges of undertaking empirical research.

The use of EI theory to make sense of my findings will be particularly valuable in educating students both as a means of explaining emotion management and relationships in practice and as a tool to help them develop skills which are likely to help them do this. Furthermore, EI skills have a wider application than the uses I have outlined in Sections 6.4.2.a. – c, particularly with regard to parts of the curricula which relate to leadership skills, understanding the behaviour of others, coping with the demands of practice and the academic pressures of the nursing programme. This will not only serve the children's nursing students at the HEI where I work but also their adult and mental health nursing student peers.

My increased understanding of the lived experience of nurses working in CHs will enable me to support staff and students in my CH link area more effectively.

### **6.10. Further research**

It would be interesting to replicate the study with nurses who work in another CPC setting, e.g. paediatric oncology, to ascertain how long-term relationships with parents are managed within that environment. Comparison with my findings would make it possible to make more concrete conclusions

about the influence of the hospice environment, particularly in relation to perceived personability requirements and counterbalances.

Having identified EI as a lens through which to explore my findings it would be interesting to return to the original participants to carry out a deductive study; one which starts with the hypothesis that approaches used by experienced CH nurses are underpinned by EI and measure this using a validated tool. The results could then be explored alongside the original transcripts.

The suggestion that the hospice features of *job satisfaction, positivity and fun* and *extraordinary peer support* may contribute to enhancing EI is also worthy of further investigation.

Patrick was the only male participant. Although he was not an outlier, some of his approaches to emotional challenges were subtly different to the other participants. Therefore, a male only study may be worthwhile. This would be particularly valuable if individual EI traits were studied, as previous research (Meshkat and Nejati 2017) found no gender difference in EI overall but there were differences in particular traits.

Some of the grey literature in the review suggested that parents see nurses in a way that extends beyond their professional role (Nahra 2008; Dolan 2013). My study identified that, from the perspective of some nurses, parents often viewed them as friends. So dyad research would enable comparison of nurses and parents' perspectives.

When presenting an outline of my findings at a CH research centre conference, parents and practitioners asked about extending this work to CH healthcare assistants. This would be an interesting proposition particularly if a comparison could be made with registered nurses and/or registered nursing associates.

### **6.11. Dissemination**

Some dissemination has already taken place. Details of this and planned activities are detailed in Table 6.6.

<b>Table 6.6: Dissemination achieved and planned</b>			
<b>Achieved</b>			
What	Where	When	How
Pilot study	Martin House Research Centre Conference	September 2018	Poster presentation
Pilot study	Local UHB Research and Development Conference	June 2019	Poster presentation
Abridged Literature Review	International Journal of Palliative Nursing	November 2019	Journal Article (Also featured in TfSL Synopsis: International digest of children's palliative care research abstracts. December 2020)
Pilot study	Together for Short Lives Conference	Scheduled for March 2020 – cancelled due to Covid. Abstract published in collection of abstracts circulated to all registered attendees	Poster presentation/ Collection of Abstracts
Findings	Martin House Research Centre Conference (online)	April 2021	Oral Presentation
Findings	Cardiff University CYP with Long-Term Conditions Research Group Seminar	June 2021	Oral Presentation
<b>Planned</b>			
Findings	Participants	December 2021	Synopsis
Findings	Pilot site (Academic link area)	September 2021	Presentation during hospice's Professional Development week
Findings (emotional and relational management)	International Journal of Palliative Nursing	By mid 2022	Journal article
As above	Together for Short Lives Conference	2022 – Date yet to be advertised	Conference presentation
Findings (Coping and counterbalancing theme)	International Journal of Palliative Nursing	By late 2022	Journal article

As above	Together for Short Lives Conference	2022 – Date yet to be advertised	Conference presentation
Findings	RCN Forums: CYP, Pain and Palliative Care	By early 2022	Infographic of Findings
Findings	Palliative Care Research Society	Early 2022	Newsletter
Children's Hospice Nurses' views of parental coping strategies (use of data set aside as not relevant to this study)	Journal of Child Health Care or Nursing Children and Young People	By mid 2023	Journal article
Using new technologies for data collection	Nurse Researcher	By late 2022	Journal article
Applied findings: Managing emotional labour, Emotional Intelligence, Professional Boundaries	UG & PG Nursing Curriculum	Ongoing	Lectures and workshops

## 6.12. Chapter summary

Within this chapter the study themes were used as a structure to explore the findings through the lens of EI, using the constructs of Goleman's EI model (1998). Supplementary literature was included where relevant and figures / tables have been used to illustrate some of the discussion.

The exploration of my findings through the lens of EI suggests that it may be an important component of successfully managing the emotional and relational challenges of CH nursing. Some of the hospice features which are counterbalances to emotional labour (*job satisfaction, positivity and fun and extraordinary peer support*) may also enhance EI, but this requires further exploration.

I have also presented suggestions for how EI could be used in recruitment/retention, staff development, formal nurse education and

practice. Revisiting the literature revealed no further research in relation to the specific focus of my study. However, there were two studies which linked with the original review. These re-highlighted emotional labour in CPC nursing, job satisfaction and the affinity parents feel with CH staff. This reinforces the value of this study to CH nursing. Hence the dissemination plan and suggestions for further research contained within this chapter. My unique contribution has been outlined in terms of the study focus, data collection methods and a suggested framework for practice. The limitations of the study are acknowledged.

## **CHAPTER SEVEN: CONCLUSION AND EPILOGUE**

### **7.1. Conclusion**

This thesis has allowed me to explore an area of personal and professional interest that is important to nursing in terms of staff wellbeing and navigation of the nurse-parent relationship. The findings provided an insight into how experienced children's hospice nurses engage emotionally with parents whilst simultaneously managing the level of involvement and maintaining a sense of separation. The findings also highlighted features of hospice work which positively contribute to counterbalancing the emotional demands of the role. Exploring the findings through the lens of EI provided a theoretical explanation for the personal traits which enabled the participants to undertake the skilful emotional and relational management they outlined.

I am excited about taking this work forward and using the research and practice knowledge I have gained to lead and inspire others. There is a breadth of literature which highlights issues arising from emotional labour and professional integrity/ boundaries in nursing but research-based strategies and solutions are less prominent. Completion of this thesis presents me with the opportunity to now share the new knowledge outlined above with nursing students and practice colleagues. In consideration of what I have discovered from the literature about low levels of EI awareness in some practice areas (Wilson, 2014), I would like to begin by developing a foundation learning package for both students and qualified nurses from associate to senior level. The knowledge acquired from this learning package could then be built upon.

Initially I would like to work on the foundation learning package with CH and other CPC practitioners. EI skills could then be further developed and refined, using the ENRiCHn framework I have created as a basis for this. In terms of transferability, I also feel there is potential for collaboration with colleagues from other fields of nursing. Using context specific examples we could work together to refine and develop the framework to improve practice elsewhere.

Alongside my passion for dissemination and further development of my research, I am mindful that doctoral study is a starting point to develop as a



researcher. My ideas and aspirations for further development will be a platform for developing collaborative funding applications to underpin post-doctoral work which aims to improve nursing practice in the areas of emotional labour and professional integrity. I will work with more experienced researchers to learn from them and to develop a portfolio of work relating to these complex areas of practice. With this in mind I have already joined the Cardiff University School of Healthcare Sciences' research theme groups 'Optimising Service Delivery and Organisation' and 'Optimising well-being and the management of long-term conditions', as these straddle the foci of my research.

## **7.2. Epilogue**

Throughout the doctoral journey I have been mindful that I came to it with existing knowledge of children's nursing and children's hospice work. It has been challenging to divorce myself from this during all stages of the work. However, by keeping a reflective diary, focusing on and being true to the participants' voices and constantly re-examining my interpretations, I believe that the findings are an accurate representation of the data collected.

Looking back to when I started my professional doctorate journey, I had a very clear idea of self-control equating to professionalism in nurse-client relationships. I have, in many ways, come full circle but with a totally different perspective. Exploring the findings through the lens of EI has enabled me to realise that traits such as self-awareness and self-regulation are vital for successful and professional management of relationships but not for the reasons of rigidity, that I had previously identified, rather the possession of highly skilled flexibility in this complex but rewarding area of practice.

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## APPENDICES

### Appendix 1: Paper published in International Journal of Palliative Nursing November 2019

#### Research

# Long-term nurse–parent relationships in paediatric palliative care: a narrative literature review

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## Abstract

**Background:** Paediatric palliative care (PPC) is an active, total approach to the holistic care of the child and family. Close, long-lasting relationships between healthcare professionals and parents in paediatric palliative care enhance quality, provide emotional support and can influence how parents manage their role in the face of uncertainty. **Aim:** To present a narrative literature review of long-term relationships between children's nurses and parents in PPC settings. **Methods:** Six databases (CINAHL, PsycINFO, ASSIA, Scopus, Medline and BNI) were searched, identifying 35 articles. A grey literature search produced seven additional relevant items. **Findings:** Four themes were identified: bonds; attachments and trust; sharing the journey; going the extra mile; and boundaries and integrity. All themes revealed an element of tension between closeness and professionalism. **Conclusion:** Gaining a greater understanding of how closeness and professionalism are successfully managed by children's palliative care nurses could positively influence pre- and post-registration nurse education.

**Key words:** ● Paediatric palliative care ● Nurse–parent relationships ● Professional boundaries ● Professional integrity

Paediatric Palliative Care (PPC) is defined as an active, total approach to the holistic care of the child and family (World Health Organization, 1998). Close, long-lasting relationships between healthcare professionals and parents in PPC are an important source of emotional support and can influence the way in which parents manage uncertainty (Rodriguez and King, 2014; Davies et al, 2017; Mooney-Doyle et al, 2017). While these relationships can enhance quality (Klassen et al, 2012; Buder and Fringer, 2016) and job satisfaction, they often carry an emotional burden; hence managing them is a challenge (Rushton and Ballard, 2011). Nurse–parent relationships in PPC are explored in this narrative literature review, which is drawn from a larger review, the latter being part of the first author's doctoral study (in preparation). This review is divided into four themes that were derived from an in-depth analysis of the literature:

- Bonds, attachments and trust
- Sharing the journey
- Going the extra mile
- Boundaries and integrity.

## Search strategy

An initial search on nurse–parent relationships in PPC elicited few hits, so it was necessary to conduct an expansive search. Subject headings and key words (Table 1) were used with Boolean operators to search the CINAHL, PsycINFO, ASSIA, Scopus, Medline and British Nursing Index databases. Year of publication parameters were 1982–2019. The rationale for choosing 1982 was the opening of the world's first children's hospice, an environment where nurse–parent relationships are often lengthy (Grinyer, 2012).

Studies that focused on PPC in areas where nurse–parent relationships were likely to be long term were included, for example, oncology, hospice, community, as were those involving complex, chronic illness, as care delivery and length of relationship is similar (Whiting, 2014). As the focus of the review is relationships during palliation but before the end of life, studies covering this phase of care were excluded. Studies in which the main focus was not nurse–parent relationships, but where the subject arose, were included. The initial search produced a total of 7488 hits. The PRISMA flowchart (Figure 1) maps

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Table 1. Subject headings and key words

Child	Palliative care	Family	Nurse
(MH "Child+")	Terminal care (subject heading)	Parents+ (subject heading)	Nurs*
Child*	Palliative care (subject heading)	Caregiver	Healthcare provider*
Paediatric*	Terminally ill patients (subject heading)	Care NI giver	Healthcare professional*
Pediatric*	Hospice	carer	"Health care provider*"
Adolescen*	Eol	Father	"Health care professional*"
Youth*	End N5 life	Mother	Nurses+ (subject heading)
Teen*	Terminal* N2 care	Mum*	Nursing staff+ (subject heading)
Young* N3 people	Dying N2 child*	Dad*	healthcare worker*
Young* N3 person	Terminal* N2 ill*	Guardian	"health care worker*"
Kid	"Life limit*"" (illness/condition?)	Legal guardianship+ (subject heading)	Nursing care+ (subject heading)
Juvenile*	"Life threatening"	Professional family relations (subject heading)	
Boy*	Hospice and palliative nursing (subject heading)	Parent*	
Girl*	Critical illness (subject heading)	Parental attitudes (subject heading)	
(MH "Minors (Legal)")	LTI		
Baby			
Babies			
Infant*			

the process of identification through to inclusion.

Inclusion of grey literature, including strategic documents, can give a broader perspective (Hopewell et al, 2007). The subject of this review particularly lends itself to this approach, as views of emotive topics may be more fully revealed through less formal avenues. Godin et al (2015) state that searching for grey literature in a systematic manner is difficult and requires specific search methods, such as hand-searching grey literature databases, customised Google searches, targeting specific websites and consulting subject experts. Therefore, the sources listed in Box 1 were searched, producing seven relevant items.

### Bonds, attachments and trust

McCloskey and Taggart (2010) and Pearson (2013) identified that longstanding relationships increased the intensity of mutual attachment between nurses and families, making PPC a unique type of nursing. Connectedness between healthcare professionals, particularly nurses, and families in PPC was highlighted by Clarke and Quin (2007), Erikson and Davies (2017), Davies et al (2017) and Beaune et al (2018).

Doe and Katz (2016) used case studies to explore emotional attachments with a client or patient. This has been identified as an issue in PPC that increases stress (Maytum et al, 2004). Doe and Katz (2016) found that when asked about emotional attachments, experienced PPC professionals strongly refuted this. Nevertheless, the case studies revealed evidence of strong

emotional involvement with children and families, particularly when the nurse identified closely with them. Interestingly, the first named author used the pseudonym 'Jane Doe' because she felt she would be labelled as unprofessional for admitting her emotional involvement. The fear of being seen as unprofessional for becoming emotionally involved with children and families seems evident in the emphasis placed on professionalism in a video blog promoting the work of children's hospice nurses (Ty Hafan, 2018a).

'We are professional nurses, the care that we give is professional but you can't help but take them to your heart'

The actions of nurses can have a profoundly positive affect on parents, as demonstrated in the personal parental accounts by Nahra (2008) and Dolan (2013). In Nahra's (2008) account, the nurses' attachment and love for the child was deemed to be as important as clinical competence. Furthermore, having a 'good day' was dependent on a nurse, with whom they had a strong bond, being on duty (Dolan, 2013). Similarly, the following quote, from a father's social media post, gives his perception of the relationship between his family and hospice nurses (Ty Hafan, 2018b).

'It's not just about a professional duty but a desire to give as much of themselves as is humanly possible ... alongside compassion, support, understanding and most of all love'

*'she felt she would be labelled as unprofessional for admitting her emotional involvement'*

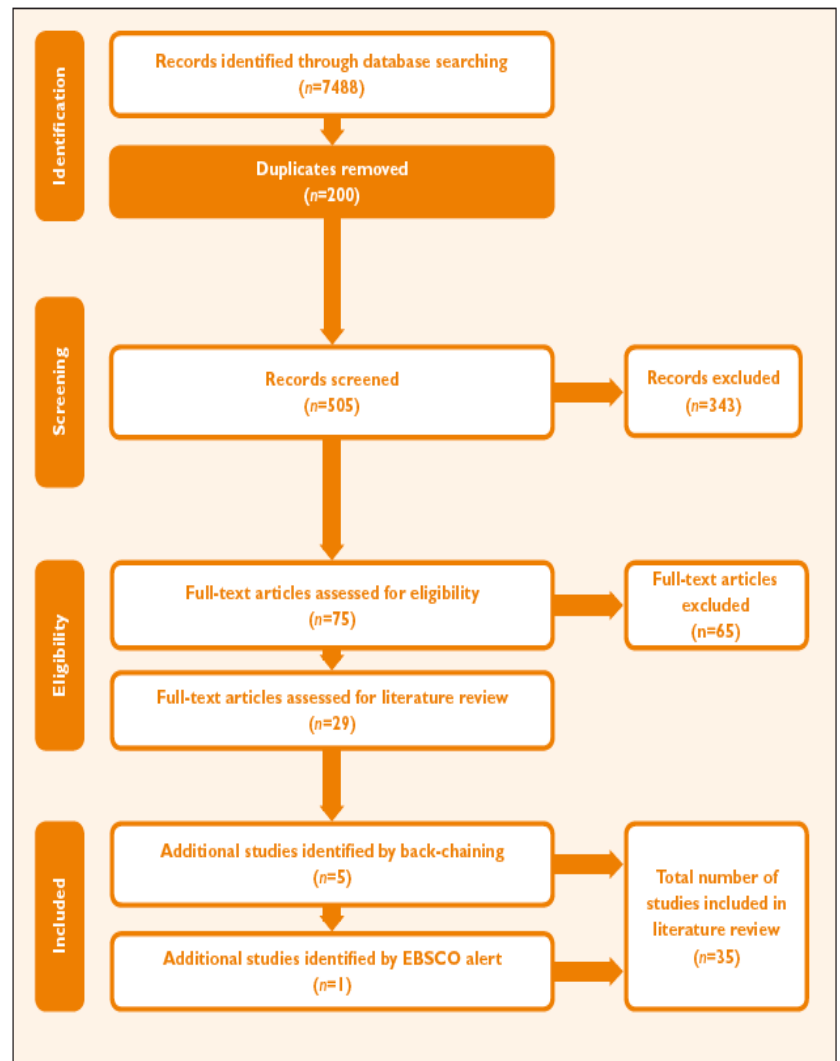


Figure 1. Search process and results using PRISMA flow diagram (Moher et al, 2009)

Neal's (2015) exploration of staff experiences of media representations of PPC also found that 'love' for children in the nurses' care was prevalent in parental perspectives. Similarly, Konrad's (2008) phenomenological study found that mothers often used the word 'love' to describe how they perceived the professional caregiver felt about their child. The word 'love' is commonly used in everyday language but when used to describe positive feelings about a child, it usually relates to something deep, long-lasting and unconditional. It is doubtful that this is, in fact, what nurses are feeling. Additionally, this is not the role of the professional nurse (Buder and Fringer, 2016).

Commonalities between nurses and particular children or parents, for example, similar background, life experiences, or ages of their

children have been found to intensify connections on the part of the family (Woolley et al, 1991) and the nurse (Doe and Katz, 2016; Erikson and Davies, 2017). Mutual respect and nurses' recognition of parental instinct and expertise, also strengthened trust and reciprocal bonds (Steele, 2002; Konrad, 2008; Rodriguez and King, 2014; Whiting, 2014; Beaune et al, 2018).

Physical contact, such as social touch and embracing, between those who have an emotional bond or attachment is commonplace (Suvilehto et al, 2015). Such physical contact has been found to be beneficial to patients and families in palliative care (McPherson and White, 2015). Pearson's (2013) UK-wide phenomenological study of paediatric oncology nurses identified that the length and depth of the relationship between nurses and families influenced whether nurses

would use physical contact as a means of comfort. Maunder's (2013) study of children's nurses delivering hospice- and community-based palliative care found that they were engaged in warm interactions and close personal contact, such as hugging colleagues, children and parents. Appreciation of this is demonstrated by parental accounts such as Nahra (2008) who recalls being regularly physically comforted by nurses during her emotional outbursts. However, McPherson and White (2015) acknowledged that this level of emotional closeness, interpersonal intimacy and engagement may be unfamiliar and uncomfortable for some in respect of professional boundaries. Conversely, Maunder (2013) found that children's hospice nurses who did not hug their peers, children and families were seen as transgressing the expected norm.

Trust is also an important factor in relationships between parents and PPC healthcare professionals (Contro et al, 2002). For example, Steele (2002) and Klassen (2012) identified that trustworthiness was fundamental to nurses being seen as 'part of the family', in that healthcare professionals working with life-limited and life-threatened children recognised the trust parents placed in them and felt privileged to be welcomed into their lives. Clarke and Quin (2007), Konrad (2008), Korzeniewska-Eksterowicz et al (2010) and Buder and Fringer (2016) discussed the role of good communication, honesty and authenticity in building relationships in PPC and as prerequisites for trust. Konrad (2008), Rodriguez and King (2014), Davies et al (2017) and Mooney-Doyle et al (2017) identified that parental trust in healthcare professionals extended to reliable advice or even trusting them make a decision on their behalf if they were overwhelmed and felt unable to do so.

### Sharing the journey

Woolley et al (1991), Rodriguez and King (2014) and Davies et al (2017) found that parents greatly appreciated healthcare professionals who would take the time to be with them, just getting to know them, talking and listening. O'Shea and Bennett Kanarek (2013) offered a case study written from a parental perspective. The major issues identified were the importance of really listening to families; effective, open, sensitive communication across all aspects of care; helping families to maintain hope—not necessarily for a cure, but for comfort, for good things to happen to their child, the family and others; and working in partnership with families. These themes, for an adapted type of hope and helping families

### Box 1. Unpublished and grey literature search

- British Library
- Conference proceedings
- Institute for Health and Social Care Research (IHSCR)
- NIH Re-PORT
- New York Academy of Medicine grey literature report
- Open Grey
- ProQuest
- International Children's Palliative Care Network website
- Together for Short Lives website
- E-Hospice website
- Hospice UK website
- Local children's hospice website
- European Association for Palliative Care website
- Worldwide Hospice Palliative Care Alliance website
- Google

navigate their journey, are supported by Smith et al (2018). Similarly Mooney-Doyle et al's (2017) study found that a major parental expectation of the healthcare professional was to empower them to carry on with their everyday lives and maintain their family relationships.

As well as featuring in empirical studies, journeying alongside families and a sense of shared history is a prevalent theme in grey literature, such as video blogs (Together for Short Lives, 2016), for example:

'...making a real difference for families and accompanying them on their journey...for me, is where the reward is...'

Being part of the family is a common theme across the literature. For example, Steele (2002) identified that becoming 'just like part of the family' was a result of being seen as trustworthy and thereby permitted to accompany the family on their journey. A recruitment campaign for children's hospice nursing also highlights this notion of becoming part of the family (Together for Short Lives, 2016) as does Johnson (2016).

This is an aspect of the nurse-parent/child relationship that needs careful management in terms of the journey belonging to the family and not the healthcare professional (Davies et al, 2017), however much they may empathise (Papadatou, 1991). Davies et al (2017) undertook a 3-year prospective grounded theory study that explored parental and healthcare professional perspectives of best practice in provider-parent interaction. A major finding was that healthcare professionals who demonstrated



best practice empathised, rather than sympathised, with parents. They defined empathising with parents as a shared experience, in which they entered the parents' story to try to understand their perspective. These 'best practice' practitioners felt that differentiating their own experiences and feelings from that of the family was integral to empathy, which was described as the ability to become a 'fellow traveller' without becoming overwhelmed by their own feelings.

### Going the extra mile

PPC staff, particularly nurses, often feel obliged to work beyond the remit of their role in relation to hours, tasks and contact with colleagues/families after the end of their shift (Kushnir et al, 1997; Erikson and Davies, 2017). Despite the personal cost of stress, work-life imbalance, home conflict, burnout and compassion fatigue, these additional duties were found to be undertaken with a sense of conscience and willingly (Rodriguez and King, 2014). Both staff and parents felt that these actions strengthened their relationship (McCloskey and Taggart, 2010; Pearson, 2013; Rodriguez and King, 2014; Davies et al, 2017). However, once these bonds were developed, nurses often felt they needed to take on even greater responsibility for the family, so that these additional activities became the norm (McCloskey and Taggart, 2010; Pearson, 2013; Rodriguez and King, 2014). Undertaking these additional duties sometimes fulfilled the nurses' need to be needed (Cargill, 2014) and gave rise to feelings of indispensability (Lattanzi-Licht, 1991). This perpetuated the behaviour, but eventually led to serious effects such as compassion fatigue and burnout (Maytum et al, 2004). Additionally, if this meets the nurses need rather than that of the child or family, it is outside the bounds of the therapeutic relationship (Roberts et al, 2015). Maguire and Price (2007) reflected on how involvement should be fluid and adaptive, depending on the families' needs. Professionals also need to beware of taking over, becoming the 'omnipotent rescuer', when the family may just need a little support (Benner and Wrubel, 1989).

A number of studies identified that additional duties were also expected by parents. This was usually couched in terms of availability and flexibility (Woolley et al, 1991; Steele, 2002; Rodriguez and King, 2014; Whiting, 2014) or a greater level of commitment (Dolan, 2013), but in essence meant that parents wanted healthcare staff to be available whenever they were needed. This was recognised by parents as 'going the extra mile', and staff who did so were highly

valued (Konrad, 2008; Nahra, 2008; Rodriguez and King, 2014). Witnessing the huge difference these actions made to families and the appreciation shown by parents further perpetuated staff self-expectation to operate over and above their designated duties. McCloskey and Taggart (2010) found that this often led to a very intense relationship between one nurse and a family, particularly for hospice nurses and community children's nurses. Such intense relationships increase stress, and it is unlikely that any one person can fulfil all the needs of a child and family (Woolley et al, 1991; Rodriguez and King, 2014).

### Boundaries and integrity

Maintaining the balance between overinvolvement and distancing oneself from families as a protective measure is an issue in nursing generally (Griffith, 2013) and has been identified in nurses working in a range of paediatric areas (Totka, 1996; Pearson, 2013; Roberts et al, 2015). Since involvement, caring and interpersonal connections form the basis of nursing, Benner and Wrubel (1989) identified that the path between overinvolvement and distancing oneself is narrow and often requires experience to navigate. Nevertheless, Cargill's (2014) qualitative exploratory study, involving six experienced paediatric oncology nurses, identified that even for this knowledgeable and skilled population there was an increased risk of violating professional boundaries, due to the length of involvement and the emotive nature of their role.

Maintenance of professional boundaries is essential in upholding the reputation of the nursing profession (Nursing and Midwifery Council (NMC), 2018). Definitions of professional boundaries vary, but most include reference to a line or an edge that should not be crossed. Most authors agree that the focus of nursing relationships must be on care and treatment (Griffith, 2013) and what is therapeutic for the child and family (Roberts et al, 2015). Some term this as the 'zone of helpfulness' existing between the extremes of over- and underinvolvement (National Council of State Boards of Nursing (NCSBN), 2018). The importance of finding the right level of professional involvement in PPC is underlined by Maguire and Price (2007). They described this as 'connected', and defined it as compassion, conscience and commitment alongside the professionalism required by the NMC Code (NMC, 2018). This is a significant challenge for children's nurses working in this field (Erikson

and Davies, 2017) and one which has been termed as an occupational hazard (Cargill, 2014).

Woolley et al (1991), Kushnir et al (1997), Maytum et al (2004) and Rodriguez and King (2014) highlighted that facilitating the parental expectations of flexibility, availability and emotional strength over long periods of time can result in healthcare professionals becoming overinvolved and overstepping boundaries. However, from Nahra's (2008) personal parental perspective, rather than interfering with the nurses' professionalism, this higher level of commitment enhanced it. Dolan's (2013) personal account of her child's 10-year healthcare journey used phrases such as 'girlfriends of mine', 'surrogate aunts, advisors and confidants' to describe nurses. She also recounted attending nurses' weddings. Dolan (2013) described her experience as truly holistic care, and clearly what occurred was highly beneficial to her and her family. Yet, it does raise the question of where work ends and personal life begins.

This is further complicated by the informality desired by some parents (Steele, 2002, Davies et al, 2017) and encouraged by some philosophies or environments of care (Woolley et al, 1989; 1991; Martinson, 1995; Ashmore and Banks, 2002). Woolley et al (1991) identified that a sense of humour and sharing a joke with children and families was an important means of forming relationships within the hospice setting. More recently Maunder (2013) found that the home-like environment of the hospice and home visiting led children's nurses working in these PPC environments to assume informal, non-traditional professional personas in order to make families feel more comfortable.

Informality does pose risks for the care relationship to be misunderstood by families. For example, they may perceive the relationship to be a friendship, with all the closeness and personal exchanges this brings. Similarly, healthcare professionals may unwittingly become drawn into conversations and situations that sit outside the therapeutic relationship outlined by Roberts et al (2015). This was evident in the study by Erikson and Davies (2017), which identified that some nurses perceived some 'extra mile' activities and contact with parents outside work as a violation of professional boundaries, while others felt that this was an extension of their role and a valuable source of support. Even those who clearly identified some of their behaviours as boundary violations felt that this could not be helped due to their attachment to the family. Participants in this study who successful

managed professional boundaries adopted behaviours that buffered them from the emotions surrounding their work, such as keeping a distance and strict separation of personal and work life. This included careful limitation of personal disclosure and always keeping the focus on the child and family.

The enhancement of bonds due to commonalities between nurses and particular children or parents identified earlier (Woolley et al, 1991, Erikson and Davies, 2017) can also pose a risk for losing perspective, erosion of a clear sense of one's role and transgression of professional boundaries (Lattanzi-Licht, 1991). Healthcare professionals can easily identify commonalities with parents because they have access to much of their personal information. However, personal disclosure on the part of the healthcare professional needs to occur for the parent to identify a commonality. Self-disclosure is a recognised part of initiating, developing, maintaining and terminating therapeutic relationships (Ashmore and Banks, 2002) and is appreciated by parents of life-limited and life-threatened children (Steele, 2002; Davies et al, 2017). However this reciprocity requires careful management and skill to discern what is appropriate and inappropriate (Lussier and Richard, 2007).

This brings one to the concept of professional integrity, which, in essence, means engaging with the values of your profession by being both 'self-regarding and other-regarding' (Rushton and Ballard, 2011). Brown (2007) and Pearson (2013) found that the uniqueness of each family and their situation meant that nurses continually reconstructed their approach to achieve holistic, bespoke care while attending to their own emotional labour and integrity. Similarly, Erikson and Davies (2017) found that maintenance of integrity is achieved when nurses integrate two competing but essential aspects of the nursing role: behaving professionally; and connecting personally. When nurses were adept, they were able to provide high-quality care within a clearly defined therapeutic relationship. The process was highly individualised to each nurse and each family. Unsuccessful mitigation of tensions led to compromised integrity, characterised by boundary breaches, compassion fatigue and burnout. Furthermore, a nurse's professional registration may be at risk should a boundary breach be deemed worthy of sanctions by their professional body.

Professional boundaries are complex and, as shown in the literature discussed here, particularly relevant to PPC nursing. Seeing



### Key points

- Close, long-lasting, therapeutic relationships between healthcare professionals and parents in paediatric palliative care are an important source of emotional support for families
- Nurses working in paediatric palliative care gain job satisfaction from developing therapeutic relationships with families but managing the emotional burden can be a challenge
- Professional boundaries can become blurred in long-lasting nurse–parent relationships, so skillful management of the relationship is required
- Management of professional boundaries can be taught to some extent but is often developed with experience. However, even experienced practitioners can find this a challenge

boundaries as straightforward, ‘black and white’ or as a defined line, is unrealistic (Erikson and Davies, 2017). Both Cargill (2014) and Buder and Fringer (2016) stressed that understanding and managing professional boundaries is something that cannot really be taught, but is learned from role models, experience and a sense of one’s own vulnerabilities and resilience.

### Summary

This review has brought together two of the parties involved in the PPC journey; parents and nurses. The literature reviewed focused on studies in which nurses made up a substantial proportion of the sample and where the parent participants were caring for a life-limited child and were currently in the long-term nurse–parent relationship rather than being bereaved.

The major themes arising from this review are: bonds, attachment and trust; sharing the journey; going the extra mile; and boundaries and integrity. It appears that the very things that enhance the nurse–parent/family relationship are those that pose the greatest challenges. This merits further exploration, particularly in the hospice setting, as contemporary studies undertaken exclusively in this environment are

rare. Gaining a greater understanding of how professional integrity and emotional labour are successfully managed by children’s nurses working in palliative care could positively influence pre- and post-registration nurse education. *JPN*

### Conflict of interest: None

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### Continuing professional development: reflective questions

- How attached am I to the children and families in my care?
- What is the difference between sympathy and empathy?
- Do I sometimes work beyond my remit to benefit children and families?
- What are my self-care strategies?
- What do professional boundaries and integrity mean to me?

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## Appendix 2: Selecting a methodology

Essentially there are five approaches to qualitative research; Ethnography, Narrative, Phenomenology, Grounded Theory and Case Study (Holloway and Galvin, 2017). Within each of these there are a number of methods that can be used to collect data. Sauro (2015) summarises the focus of each, as show in the table below:

<b>Differences between the five qualitative approaches (Sauro, 2015)</b>	
<b>Method</b>	<b>Focus</b>
Ethnography	Context or culture
Narrative	Individual experience & sequence
Phenomenological	People who have experienced a phenomenon
Grounded Theory	Develop a theory from / grounded in field data
Case Study	Organization, entity, individual, or event

All of the above were possibilities for this study but Holloway and Galvin (2017) state that it is important to consider the following when choosing an approach:

- The nature and type of the research question or problem
- The epistemological stance of the researcher
- Skills and training of the researcher
- The resources available for the research project

This supports a practical as well as a philosophical approach to the design of the project and certainly the practicalities of undertaking a part time doctoral study whilst working full time in a senior role has necessitated a pragmatic approach to the last of these points. Considerations given to each of these methods are discussed below.

My early thoughts were focused on professional boundaries in terms of some sort of 'line' that children's nurses working in hospices either crossed, violated (Hartlage, 2012) or maintained. Essentially though, what I was really interested in is the long-term relationship between the nurse and parents within the CH setting. This long-term relationship in a 'homely' environment'

was considered to be unique by the stakeholders I consulted but may have commonalities with other professions, e.g. police liaison support officers, child protection social workers. However, police liaison support officers and child protection social workers would be delivering services in the client's home rather than in a health and social care facility which is specifically designed to mirror a home environment. Therefore, the dynamic is different, in that the hospice is primarily the domain of the provider into which the children and families are invited. This means that the 'power balance' in the relationship favours the staff in the same way as it does in a hospital (Corless et al. 2016).

At the start of my journey on the professional doctorate programme I had considered using an ethnographical approach. Ethnography is a research method in which the researcher immerses themselves in a setting for a period of time. The researcher observes behaviour and what is said (Bryman, 2016) There is usually a second phase to data collection, normally interviews (Holloway and Galvin, 2015). Observing interactions between parents and nurses would have given some indication of situations which were emotionally charged and where the nurse may find it difficult to manage professional integrity and boundaries. However, the observer would find it difficult to ascertain, at the time of observation, whether the nurse and the longevity of relationship with the family met the inclusion and exclusion criteria. It may have been possible to explore specific interactions in more depth via a follow up interview. However, there was firstly no guarantee that the nurse being observed would agree to participate in the interview stage so this linking behaviour and 'in the moment' thoughts to deeper exploration at a later date may not be possible. Furthermore, the time lapse between the extended period of observation and the interview may have made recall difficult and when specifically questioned about an interaction with a parent the nurse may edit their response in order to outline what they perceive to be the most professional approach. I was also conscious that I may make judgements about the management of emotional labour and maintenance of professional integrity based on observed behaviours when in fact the behaviours may not be truly reflective of thought processes, sense making

and decision making. Ethnography did offer some aspects that may have gone some way to answering the research question, namely the interview phase. However, there were too many 'risks' surrounding the fit between the researcher actually observing interactions between individuals who met the inclusion criteria and the linking of suitable interactions with a participant who would take part in the interview phase.

Phenomenology is defined as a philosophical approach which explores the study of consciousness and the meaning of an individuals' lived experience through their own description (Holloway and Galvin, 2017). This approach seemed to offer a good fit for a study which sought to explore individual CH nurses' thoughts about interactions with parents of life-limited/life-threatened children they have known for some time. The sample size required for such a study, i.e. 5-25 (Sauro, 2015) would have been manageable and a semi-structure interview approach facilitative of an exploration of the participants' experience. Therefore, this approach had the potential to answer the research question via participant descriptions which would have given an insight into their consciousness when talking about emotional labour and professional integrity. This approach, like many others, relies on participants' own perspectives to provide insight into their motivations (Galvin and Holloway, 2015). So I was concerned about the reliability of the data in terms of selectiveness of recall in relation to both the scenario(s) the participant chose to discuss (if indeed they did chose a scenario rather than a general discussion) but more importantly the length of time which would elapse between the chosen scenario and the interview. A scenario which the participant feels is relevant to the study may have occurred some time ago and although this may still be vivid, the memory of thought processes, decision making and sense making may have become very blurred over time. The participant may have even 'reinvented' the story in their own mind in order to rationalise their own or others' behaviour and/ or to make the situation more bearable. The participant may also find it difficult to recall the duration of time for which they had known the family at the specific juncture of the interaction. So, it's suitability in terms of the inclusion criteria may be doubtful. A Phenomenological approach was a serious consideration for



quite some time but ideally I wanted something which would enable a closer link (in time) between the suitable scenario, the recording and the more in-depth exploration of these via interview.

Grounded Theory is an inductive approach from which hypotheses and theories emerge i.e. are 'grounded' in data (Parahoo, 2006). Grounded theory research is undertaken by collecting and analysing data simultaneously, with the goal of developing a new theory (Gerrish and Lathlean, 2015). Data sources for grounded theory research are varied and can include interviews, observations, documents and visual and oral presentations or events (Holloway and Galvin, 2017). The same difficulties outlined in the discussion of ethnography and phenomenology above would apply to grounded theory, for the same reasons. Documents would be of limited value as information contained within medical notes, care plans/evaluations would be sparse in terms of content surrounding nurse/parent interactions. Furthermore, any content which did include this would be very unlikely to reveal any depth of internal dialogue on the part of the nurse (nor would it be appropriate for this to be included). Visual and oral presentations may provide some insight but would need to be very specific to the research question, in which case they are unlikely to occur naturally. Events in terms of an interaction between a nurse and a parent would fit but the term event would imply that this is extraordinary rather than an everyday occurrence in practice. This may have prompted participants to select particularly dramatic encounters which would inflate and magnify thoughts and feelings and may alter the usual decision-making process. What was sought was the everyday, constant, moderate intensity of emotional labour and management of professional relationships with parents. In addition, the larger sample size required for a Grounded Theory study, i.e. 20-60 (Sauro, 2015) was not practical in relation to the resource and time constraints of the project.

Case Studies are a common approach in qualitative research (Stake, 2000). Data can be collected via interviews, documents, reports and observations relating to organisations, entities, individuals or events (Sauro, 2015). A Case Study approach was considered with analysis within and across case studies. However, the difficulties outlined above in relation to ethnography,

phenomenology and grounded theory also apply to case study interviews and observations. Furthermore, the value of other sources, such as reports and documents, e.g. care plans/ evaluations, would be limited for the same reasons as outlined in the discussion on Grounded Theory above. Therefore, I selected the narrative interpretive approach outlined in Section 3.5.4. of the thesis.



## Appendix 3: Participant Information Sheet



### School of Healthcare Sciences, Cardiff University

Chief Investigator: Mrs Mandy J Brimble

Supervisory Team: Dr Sally Anstey and Dr Jane Davies

Room 2F16 Cardigan House

Heath Park

Cardiff

CF14 4XN

Email: [brimblemj@cf.ac.uk](mailto:brimblemj@cf.ac.uk)

Phone: 02920687701

**Study title: Long-term nurse-parent relationships in the children's hospice setting**

Dear nurse

I would like to invite you to take part in a Professional Doctorate research study which will explore how nurses manage long-term relationships with parents of children they care for within the hospice setting.

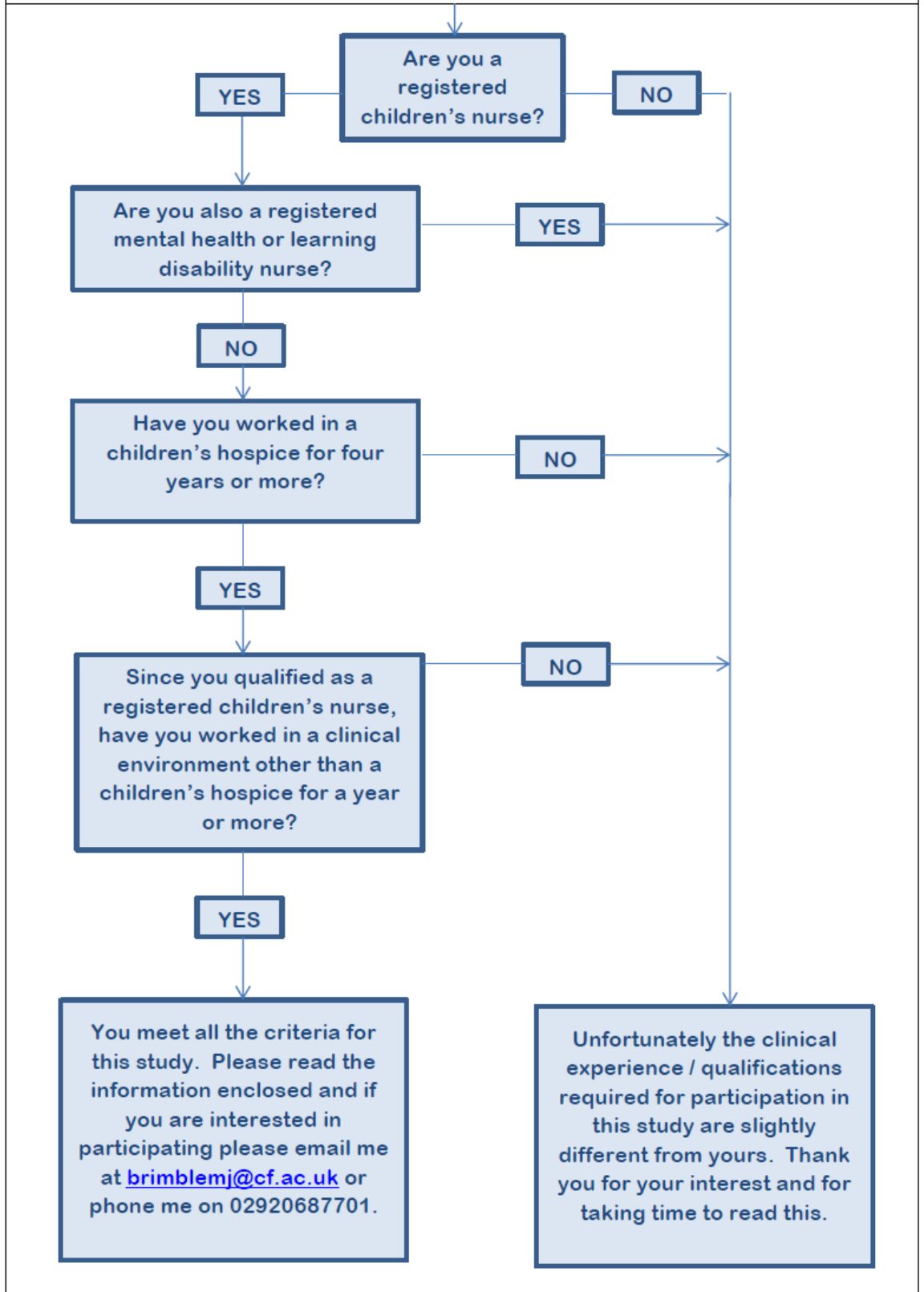
Enclosed is an information sheet explaining more about how the study will be undertaken. Before you spend time reading this, could I please ask you to use the flow chart (Box 1) to decide whether you meet the inclusion criteria for the study.

Participation in the study is completely voluntary. The enclosed information should provide everything you need to know about the study but if you would like to discuss this further I would be happy to speak with you on the telephone. Please don't hesitate to ring me on 02920687701 or email me at [brimblemj@cf.ac.uk](mailto:brimblemj@cf.ac.uk) with details of your telephone number and preferred times/dates for me to make contact with you.

Kind regards

Mandy Brimble

**Box 1: Flow chart**



**School of Healthcare Sciences**  
**College of Biomedical and Life Sciences**  
**Participant information sheet**

**Long-term nurse-parent relationships in the children's hospice setting.**

I am an experienced children's nurse and academic undertaking a Professional Doctorate. I would like to invite you to take part in my research study which explores how children's nurses manage long-term professional relationships with parents when working in children's hospices. It is recognised that this is a unique environment providing highly specialised care. Due to the nature of care delivery, emotional labour is high and as the philosophy of children's hospices is to care for the whole family; this will include your relationship with parents.

Before you decide whether or not you want to take part, I would like to explain why the study is being done and what it will involve for you. Please take the time to read the following information carefully.

**What is this study about?**

You are probably aware that Together for Short Lives define the care delivered by children's hospices as follows:

*a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services.*

(Together for Short Lives, 2016a, p1)

In essence this means that children's nurses are required to provide emotional, social and spiritual palliation, to families as well as to children alongside the physical palliation of the child's symptoms. Although much of this work is undertaken by members of the multi-disciplinary team who have a remit for family support, children's nurses often spend extended periods of time with parents who will discuss their thoughts and feelings about their child's life-limiting condition and what it means for them as a family. Although the RCN (2018) provide competencies for working in CPC, there is no extensive formal guidance on how to provide the emotional, social and spiritual care families need, whilst maintaining professional integrity and without exceeding one's own capacity for emotional labour.

This study will explore how children's nurses who have worked in the hospice environment for a significant period of time (four years or more) manage long-term relationships with families (those whom they have known for at least three years). This means that I will be exploring the practices of experienced children's nurses who have established relationships with families. I am very interested in how children's nurses respond to the challenges of working with parents who's child is predicted to die before the age of eighteen over long periods of time, specifically children who attend the hospice regularly for short break or day care. I am also interested in the types of coping strategies experienced nurses develop and use to ensure they can continue to work in this demanding field of practice.

The research question for the study is:

How do children's nurses working in hospices manage emotional labour and professional integrity in long-term relationships with parents?

The aim of the study is to:

Develop an in-depth understanding of how children's nurses manage long-term relationships with parents in the children's hospice setting.

### **Why have I been invited to take part?**

I am inviting you to take part because you are a children's nurse working in a hospice with the background, experience and qualifications necessary to provide a commentary on managing the nurse-parent relationship within this unique setting.

### **Do I have to take part?**

No. It is entirely your decision whether or not you want to join the study. If you are interested you will receive further information and if you decide to participate I will ask you to sign a consent form confirming your agreement to be involved in the study. If you wish to withdraw from the study you can do so at any time and you are not obliged to give a reason for doing so. If you decide to withdraw from the study, with your permission, I would like to keep and use any information that you have provided whilst taking part in the study.

### **What will happen to you if you take part?**

Once you consent to take part in the study you will receive detailed information on how I will collect the information I need. You will be asked to complete two audio diaries, ideally over a period of one to three months. A telephone interview will take place soon after you have submitted each audio diary to me. This will be to discuss and explore the content of the diary so

that I can fully understand the situation, how you felt about it, what was good and not so good about your interactions with the parent on that day. The audio diaries will be collected via your mobile phone (if you have one), using the *voice memo* or *voice recorder* function. This will then be securely transmitted to me using WhatsApp. WhatsApp is a secure method of transmitting data because it offers 'end to end' encryption (you can get more details by visiting <https://www.whatsapp.com/security/>). If you do not have a mobile phone or do not have one capable of recording your voice then you will be provided with a Dictaphone and micro cassettes as an alternative. If you would prefer not to use your mobile phone for this purpose you will also be provided with this alternative. The telephone interviews will take place at a time to suit you and I will telephone you, thus bearing the cost of the call.

For each audio diary you will be asked to select a parent whom you have known for three years or more and have cared for their child regularly over this period of time, either during short breaks or day care. You will be asked to make your recording as soon as possible after the end of the shift spent caring for the selected child and family. As long as the parent meets the criteria outlined at the beginning of this paragraph the selection is entirely up to you.

The audio diaries can be as long or short as you like. Some brief guidance on what could be included will be given to help you get started but it really is up to you what you talk about. The telephone interviews will take no more than 45 minutes and will be audio taped.

### **Expenses and payments**

You will not be paid to participate in the study.

### **What are the possible disadvantages and risks of taking part in the study?**

There are no significant risks or disadvantages for you if you take part in the study. Due to the nature of your work and the things I will be asking you to consider when talking to me, you may find this upsetting. If this occurs you are free to suspend recording your audio diary or the telephone interview until you feel able to continue. In addition I would urge you to seek support via the usual mechanisms of internal and external clinical supervision provided by your institution. It might be that some of the information that you discuss will be sensitive and personal to you. However all the material collected for the study will be confidential and when the study is written up for submission of the thesis, publication or for a conference presentation your name will be changed to protect your identity. All of the information collected in the study will also be securely stored and subsequently destroyed, in adherence with the Cardiff University Research Integrity and Governance Code of Practice (2015).

**What are the possible benefits of taking part?**

On a personal level, talking about how you manage your relationship with parents will give you the opportunity to reflect on what you do well and areas you may want to improve upon. Not only will this help you to develop personally and professionally, it will also provide you with an opportunity to formalise your reflections as a means of meeting the NMC Revalidation requirements.

On a broader level the findings of the study will help other nurses to consider how they manage emotional labour and professional integrity. It will also help to inform children's hospice managers about the type of support and training required for children's nurses to thrive whilst working in a demanding, highly specialised area. It may also help to inform care delivery in other areas where nurses are in long-term professional relationships with patients/clients and their families.

**Will my taking part in this study be kept confidential?**

The procedures for handling, processing, storage and destruction of your data will meet the requirements of the Data Protection Act 2018. The identity of your organisation will not be known, and your identity will be protected. We will follow ethical and legal practice and all information about you will be handled in confidence. Audio diary files will be retained on an external drive kept in a locked cupboard in a locked room and retained for fifteen years. Anonymous transcribed data will be securely stored in a file using a coded identification number. This will be held on a secure drive accessible only to the named researchers. If you wish a copy of the transcription please let us know. Representatives of the project sponsor, Cardiff University, will be able to access the data for regulatory/audit purposes.

**What will happen to the results of the research study?**

It is important that you know your identity will not be revealed in any publication, conference presentation or the doctoral thesis without your consent. The completed thesis will be submitted to Cardiff University and subject to internal and external examination. I would like to retain the results of the study with a view to undertaking more research in this field, present the findings at conferences and develop teaching materials for pre and post registration nurses. I will also provide a report of the findings from the study for all participants.

**Who is organising and funding the research?**

The study is being undertaken as part of a Professional Doctorate Programme. The funding for the research project part of the programme is being provided by Cardiff University. The study is being supervised by two senior and experienced staff, Dr Sally Anstey and Dr Jane Davies.

### **Who has reviewed this study?**

The study has been reviewed by the Cardiff University School of Healthcare Sciences Research Ethics Committee who have approved the study.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you should speak to Mandy Brimble, Sally Anstey or Jane Davies and we will do our best to answer your questions. If you wish to express concern to someone not involved in the project, you should contact Dr Kate Button, Director of Research Governance at Cardiff University School of Healthcare Sciences. You can write to Dr Button at the School of Healthcare Sciences, Cardiff University, Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB or contact her by either telephone on 02920 687734 or by Email: [buttonk@cardiff.ac.uk](mailto:buttonk@cardiff.ac.uk)

### **What will happen if I don't want to carry on with the study?**

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far may not be able to be erased and this information may still be used in the project analysis. If you wish us to destroy any previous interview material collected, please email us to this effect and we will try to do so.

### **Further information and contact details**

You may want some more general or specific information about this study. If so please contact me.

Mandy Brimble  
Professional Doctorate Student  
Cardiff University  
School of Healthcare Sciences  
College of Biomedical and Life Sciences  
Room 2F16 Cardigan House  
Heath Park Campus  
Heath Park  
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#### **Appendix 4: The Pilot study**

Pilot studies are valuable in helping to shape and refine methodological and practical issues and have been shown to be particularly useful in the personal development and competence of novice researchers (Wray et al. 2017). Following approval by the Clinical Governance Committee of a local children's hospice, the Director of Care agreed that two self-selected nurses, who met the inclusion criteria would be permitted to take part in piloting the data collection methods. Participant information sheets (Appendix 3) were left with the Head of Care to distribute to potential participants. Initially there was no response but once individuals were reminded by this senior member of staff I quickly recruited the two participants required for the pilot. This demonstrates the potentially positive influence of the gatekeeper during recruitment (McFadyen and Rankin, 2016).

The aim of the pilot was to test the clarity of the guidance sheet (Appendix 6) and the ease of using a mobile phone to record diaries in a timely fashion, following an interaction relevant to the study. The ease or otherwise of users transmitting the audio recordings to me was also tested in order to highlight any likely technological issues. A questionnaire which explored the method of data collection (Appendix 7) was sent to pilot site participants and the feedback was used to amend and improve the guidance sheet (Appendix 6). This approach is similar to that taken by Kenten (2010) and Crozier and Cassell (2015) in exploring how participants felt about (a) keeping the diary and (b) the usability of this data collection tool. However, in these instances this was part of the study rather than a pilot. Nevertheless, the questionnaires used in these studies (Kenton, 2010, Crozier and Cassell, 2016) were useful in informing the development of my audio diary guidance (Appendix 6). In fact, Bell and Waters (2014) state that, for data collection involving diaries, piloting of returns forms and instructions to participants is essential. In the unlikely event that the data collection tool proved to be unsuitable then the mobile phone option would have been replaced by a Dictaphone. The successful use of audio diaries recorded on mobile phones and transmitted by WhatsApp in the pilot was also useful when recruiting to



the main study as I was able to provide assurances about ease of use and efficacy.

In addition to minor amendments to the audio diary completion guidance (Appendix 6) the outcomes of the pilot were that the original requirement for three audio diaries and three telephone interviews, undertaken over a three to six month period were reduced in number to two and a duration of one to three months. This occurred due to feedback from pilot participants in relation to the commitment alongside their work and the lack of urgency implied by the lengthy timespan, resulting in them failing to remember to complete the audio diaries. The telephone interviews were dependent upon completion of the audio diaries so it was important to make completion of the audio diaries manageable and keep the project on the participants' 'radar'. It is important to recognise that research will never be as important to the participant as the researcher and although incentives can increase engagement, particularly when the participant is required to send something to the researcher (Saks and Allsop, 2013), this can be considered slightly controversial (Gray, 2014). Reminders can help but need to be carefully managed to avoid placing undue pressure on participants (Thomas, 2015). Gentle, carefully worded reminders were relatively successful in the pilot, so this approach was continued to the main study.

From a practical point of view, transcribing audio diaries and telephone interviews for the pilot was good practice in refining my skills in terms of accuracy, particularly noting nuances, and speed. My reflective journal was useful in terms of developing my skills as a researcher generally and specifically in relation to the data collection methods used for the project. I noted a number of behaviours and actions which were modified to improve the main study. Firstly when transcribing the telephone interviews I noted that I talked almost as much as the participant. I made a conscious effort to speak much less during this phase of the main study, often just using acknowledgements such as 'right' or 'mmm' and encouragements, e.g. Uh huh until it was clear that the participant had finished speaking. Furthermore close listening to the pilot telephone interview recordings revealed that, on occasions, the participant seemed to have been trying to interrupt me whilst I

was asking a question. I didn't notice this at the time of the telephone interview; had this been a face-to-face interview I would have been likely to pick up on non-verbal cues that the participant wanted to speak. Of course the absence of non-verbal cues is a disadvantage of telephone interviews. However, the evaluation of the pilot revealed that neither participant would have preferred a face-to-face interview. Therefore, I adapted my approach to asking questions, or indeed during any time when I was speaking, to ensure that I was listening very carefully for any sound made by the participant. This is important as suppression of narratives can occur if the interviewer interrupts the participant or appears not to be listening (Esin, 2011).

The pilot also helped me to refine my approach to formulating telephone interview questions based on the content of the audio diaries. On transcription of the telephone interview recordings I noted that some of the questions were not entirely focused on the research question and aims. I had included them because I was interested in something the participant had said. This is a risk of both taking such an unstructured approach to the diary structure and being a novice researcher. So for the main study I was much more vigilant about maintaining the focus and took more time and greater care in deciding on the questions asked.

Maintaining focus was also important when issues unrelated to the research question were raised by the participant during the telephone interview. My natural curiosity often led to exploring something the participant had said in more detail. On transcribing the pilot telephone interviews I often asked myself why I had pursued this topic, wasting both my own and the participants' time by talking about an unrelated aspect of hospice work. I realised that this was often because it was something I was interested in as a nurse rather than a researcher, highlighting the importance of separating these two roles when undertaking studies (Price and Nicholl, 2013). However, there were occasions when the participant raised something which appeared to be only marginally related to the research but on further exploration transpired to be very relevant. Undertaking the pilot helped me to balance this and more readily identify when the participant was veering away from the point and bring them back to focus. The pilot evaluation did reveal

that participants appreciated the audio diary compilation and telephone interviews as a means to reflect upon and talk about their practice, so perhaps the deviations from focus were not entirely of my own making.

The findings of the pilot were not analysed in any detail as the main aim of the pilot was to test the feasibility of the technology and guidance for its use. Broadly speaking there was some evidence of challenges in managing emotional labour. Where relationships were very lengthy there was a sense of a shared history and at times this led to high levels of personal disclosure. Participants felt compelled to share personal information with parents as a reciprocal gesture for what families had shared with them. The hospice model of care where 1:1 nurse/child allocation is the 'norm' also fostered more social relationships between nurses and parents. Trust between the nurse and the parent was the overarching concept underpinning both the strength and harmony of their relationship and the level of the nurses' personal disclosure. Nurses often viewed the personal information shared as 'snippets' but at times this was very personal and highly emotive.

The pilot study was presented as a poster at two conferences (see Dissemination Plan in Chapter 6) and both versions are included below.

## How do children's nurses working in hospices manage emotional labour and professional integrity? : A pilot study

Mandy Brimble, Senior Lecturer and Professional Doctorate Student, School of Healthcare Sciences, Cardiff University. Email: [brimblemj@cf.ac.uk](mailto:brimblemj@cf.ac.uk)  
Supervisors: Dr S Anstey & Dr J Davies



**Background:** Children with complex life-limiting conditions are living longer<sup>1</sup> so relationships between nurses and families can sometimes span decades. There are tensions between closeness and professional distance in paediatric palliative care<sup>2</sup> and emotional labour is high<sup>3</sup>. Although emotional labour and professional integrity in long term relationships between nurses and children/families in paediatric palliative care has been researched<sup>4,5</sup>, studies undertaken exclusively in children's hospices are rare. Therefore the influence of this unique environment on nurse/parent relationships is unexplored. **Aims:** · Develop an in-depth understanding of how children's nurses manage long term relationships with parents in the children's hospice setting · Develop an in-depth understanding of how children's hospice nurses maintain professional integrity whilst providing long term practical, emotional, social and spiritual care to parents · Explore the coping strategies used by children's nurses to manage emotional labour whilst working in the children's hospice setting.

*'So I think you've got to talk about something to do with your life. Even if it's the tiniest little snippet' (P1)*

### Methods:

Data was collected via audio diaries recorded on a mobile phone and explored further by telephone interviews. Participants discussed episodes of care which occurred either as part of day or short-break care. End of life care interactions were not included. Data was securely transmitted to the researcher via 'WhatsApp'. Each participant was asked to complete 3 recordings over a 3-6 month period.

The pilot study, involving two participants, was carried out to test efficacy of technology and clarity of participant guidance for transmission of data. All aspects of the pilot study mirrored the main study..

The main study is about to commence and this will involve a purposive sample of eight children's nurses, working in a children's hospice.

### Pilot Study: Early Findings:

There was some evidence of challenges in managing emotional labour. Where relationships were very lengthy there was a sense of a shared history and at times this led to high levels of personal disclosure. Participants felt compelled to share personal information with parents as a reciprocal gesture for what families had shared with them. The hospice model of care where 1:1 nurse/child allocation is the 'norm' also fostered more social relationships between nurses and parents. Trust between the nurse and the parent was the overarching concept underpinning both the strength and harmony of their relationship and the level of the nurses' personal disclosure. Nurses often viewed the personal information shared as 'snippets' but at times this was personal and highly emotive.

*'It's because we have a close relationship and she sort of knows more about me' (P2)*

### References

1. Cooper, J. 2017. Palliative and End of Life Care for Children. In: Woodthorpe, K. Death, Dying and Devolution. Bath, UK. Institute for Policy Research, University of Bath, pp. 15-21.
2. Buder, R and Fringer, A. 2016. Paediatric palliative nursing: the tension between closeness and professional distance. *European Journal of Palliative Care*. 23 (6), pp 278-280.
3. Maunder, E. 2006. Emotion work in the palliative nursing care of children and young people. *International journal of palliative nursing* 12(1), pp. 27-33.
4. Maunder, E. 2013. Exploration of the emotion management of children's nurses providing palliative care for children/young people living with life-limiting conditions and their families. Swansea University [Online] Available at: <http://www.wspcr.ac.uk/phd-studies-maunder.php> [Accessed 31.3.17.]
5. Erikson, A. and Davies, B. 2017. Maintaining Integrity: How Nurses Navigate Boundaries in Pediatric Palliative Care. *Journal of Pediatric Nursing*, 35, pp. 42-49.

## Long term nurse-parent relationships in the children's hospice : A pilot study

Mandy Brimble, Senior Lecturer and Professional Doctorate Student,  
School of Healthcare Sciences, Cardiff University. Email: brimblemj@cf.ac.uk  
Supervisors: Dr S Anstey & Dr J Davies



**Background:** Children with complex life-limiting conditions are living longer<sup>1</sup> so relationships between nurses and families can sometimes span decades. There are tensions between closeness and professional distance in paediatric palliative care<sup>2</sup> and emotional labour is high<sup>3</sup>. Although emotional labour and professional integrity in long term relationships between nurses and children/families in paediatric palliative care have been researched<sup>4,5</sup>, studies undertaken exclusively in children's hospices are rare. Therefore the influence of this unique environment on nurse/parent relationships is unexplored.

### Pilot Study Aim:

- To test the efficacy of the data collection technology and clarity of guidance for data transmission.

### Main Study Aims:

- To develop an in-depth understanding of how children's nurses manage long term relationships with parents in the children's hospice setting.
- To develop an in-depth understanding of how children's hospice nurses maintain professional integrity whilst providing long term practical, emotional, social and spiritual care to parents.
- To explore the coping strategies used by children's nurses to manage emotional labour whilst working in the children's hospice setting.

### Methods:

Data were collected via audio diaries, recorded on mobile phones. Participants completed each diary after an episode of caring for a child and family whom they had known for at least 3 years. Diaries related to short break or day care but not end of life. Data were securely transmitted using 'end to end' encryption via 'WhatsApp'. Each participant was asked to complete 3 diaries, over 3-6 months. Diaries were further explored in telephone interviews.

### Audio diary and telephone interview pilot evaluation (Extract from questionnaire)

	Yes %	No %
Q3. Was the guidance for recording the audio diary clear?	100	0
Q4. Were the instructions for transmitting the audio diary clear?	100	0
Q5. Was it easy to record your thoughts and feelings in the form of an audio diary?	100	0
Q10. Did you find this method of data collection intrusive?	0	100
Q18. Were the telephone interviews a useful way of expanding on your audio diary	100	0
Q20. Would you have preferred to be interviewed face to face	0	100

**Figure 1: Extract from participant guidance**

**SECTION 1: Making and sending your audio diary using an iPhone.**  
If you are using an Android phone, please see later instructions. There are two options for using an iPhone to record and send your audio diary. One is to record a Voice Memo and then send it as an attachment via WhatsApp the other is to record and simultaneously send via WhatsApp. I will talk you through the first option then the second.



Using an iPhone Option 1: Recording a Voice Memo and then sending via WhatsApp

Use the 'Voice memos' function usually located in Utilities, here



1. Open the 'Voice Memos' app



2. Tap the red record button to start recording the voice or audio, when finished tap again on the same button to stop recording.



### Q16. What did you like best about recording an audio diary?

*Chance to talk and reflect (P1)*

*It made me reflect more on the conversations I had with the families (P2)*

### Q17. What did you like least about recording an audio diary?

*Finding time to do it (P1)*

*I found it hard to find the time to do it ...after nights or after a run of long days (P2)*

**Outcome:** This feasibility pilot was carried out in preparation for a Professional Doctorate research project. It tested the efficacy of the technology and guidance for data transmission. Two eligible children's nurses participated and evaluated their experience. Their evaluations led to amendments to the study protocol. Diaries and telephone interviews were reduced to 2 and the timeline to 1-3 months. Minor changes were made to the participant guidance.

### Pilot Study Findings:

- Some challenges in managing emotional labour but the 'home from home' hospice environment an philosophy helped to mitigate this.
- Where relationships were very lengthy there was a sense of shared history and occasionally this led to high levels of personal disclosure.
- 1:1 nurse to family allocation fostered social relationships between nurses and parents
- Trust between the nurse and parent was an overarching concept.

### Conclusion

- The pilot demonstrated that the main study is feasible and rigorous
- Perceived obligations of reciprocity may be an indicator of fluid professional boundaries
- Nurse-parent relationships in the children's hospice setting require careful management.

*'So I think you've got to talk about something to do with your life. Even if it's the tiniest little snippet' (P1)*  
*'It's because we have a close relationship and she sort of knows more about me' (P2)*

### References

- Cooper, J. 2017. Palliative and End of Life Care for Children. In: Woodthorpe, K. Death, Dying and Devolution. Bath, UK: Institute for Policy Research, University of Bath, pp. 15-21.
- Buder, R and Fringer, A. 2016. Paediatric palliative nursing: the tension between closeness and professional distance. *European Journal of Palliative Care*, 22 (6), pp.279-280.
- Maurnder, E. 2006. Emotion work in the palliative nursing care of children and young people. *International Journal of palliative nursing* 12(1), pp. 27-33.
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## Appendix 5: Consent Forms

### Appendix 5a: Consent Form a (Audio diaries)

School of Healthcare Sciences

College of Biomedical and Life Sciences



**Title of Project:** Long-term nurse-parent relationships in the children's hospice setting

**Researcher:** Mandy Brimble

#### Consent Form a – Audio diary participation

**Please  
initial  
box**

1. I confirm that I have read the participant information sheet 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 a reason. I understand any decision to withdraw and reasons given (if any) will remain confidential.

☐

3. I understand that my audio diary will be recorded on my mobile phone, another digital device or something similar, e.g. audio cassette. I agree to participate using this method of recording my thoughts.

☐

4. I understand that the audio diary recording will be transferred using secure methods of transmission.

☐

5. I understand that data collected will not be transferred to any commercial organisation but may be used anonymously for publication in healthcare journals, presentation at conferences, for teaching purposes and for future studies. This data will be securely stored for a period of 15 years. I give permission for this.

☐

6. I understand that in the unlikely event that any practice which is unsafe (that which endangers the child/ family) or is concerning (that which compromises professionalism or negatively impacts on the nurse) is revealed, then as a registrant the principal researcher is obliged to act on this (NMC, 2018) and will inform the appropriate person at the study site.

☐

7. I agree to take part in the above study

☐

Please turn over

**A few questions about you:**

How long have you been a registered children's nurse?	
Is this your only registration?	
How long have you worked in the children's hospice setting?	
Which other clinical areas did you work in, as a registered nurse, before starting work in a children's hospice (general description, <u>not specific</u> , e.g. oncology rather than the name of the ward or hospital)	
Which age bracket are you in? Age 30 or below Age 31-35 Age 35-40 Age 41-45 Age 46-50 Age 51-60 Age 61+	Please indicate a,b,c,d,e,f,or g
Contact email	
Mobile telephone number (essential for audio diary file sharing via WhatsApp)	

Name of participant: .....

Signature: .....

Name of person taking consent : Mandy J Brimble.

Signature: .....

<b>For researcher use only</b>	
Participant identification code	

### **Further information and contact details**

You may want some more general or specific information about this study. If so please contact me.

Mandy Brimble  
Professional Doctorate Student  
Cardiff University  
School of Healthcare Sciences  
College of Biomedical and Life Sciences  
Room 2F16 Cardigan House  
Heath Park Campus  
Heath Park  
CF14 4XN  
Tel: 02920687701  
Email: [brimblemj@cf.ac.uk](mailto:brimblemj@cf.ac.uk)

If you have a concern about any aspect of this study, you should speak to Mandy Brimble, Sally Anstey or Jane Davies and we will do our best to answer your questions. If you wish to express concern to someone not involved in the project, you should contact Dr Kate Button, Director of Research Governance at Cardiff University School of Healthcare Sciences. You can write to Dr Button at the School of Healthcare Sciences, Cardiff University, Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB or contact her by either telephone on 02920 687734 or by Email: [buttonk@cardiff.ac.uk](mailto:buttonk@cardiff.ac.uk)



**Appendix 5b: Consent Form b (Telephone interviews)**  
**School of Healthcare Sciences**  
**College of Biomedical and Life Sciences**



**Title of Project: Long-term nurse-parent relationships in the children's hospice setting**  
**Researcher: Mandy Brimble**  
**Consent Form b – Telephone interview participation**

**Please  
initial  
box**

1. I confirm that I have read the participant information sheet 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 a reason. I understand any decision to withdraw and reasons given (if any) will remain confidential.

☐

I understand that the telephone interview will be recorded on a digital device. I give permission for this.

☐

3. I understand that data collected will not be transferred to any commercial organisation but may be used anonymously for publication in healthcare journals, presentation at conferences, for teaching purposes and for future studies. This data will be securely stored for a period of 15 years. I give permission for this.

☐

4. I agree to anonymised verbatim quotes being used in any written outputs/conference presentations.

☐

5. I understand that in the unlikely event that any practice which is unsafe (that which endangers the child/ family) or is concerning (that which compromises professionalism or negatively impacts on the nurse) is revealed then as a registrant the principal researcher is obliged to act on this (NMC, 2018) and will inform the appropriate person at the study site.

☐

6. I agree to take part in the above study

☐

Please turn over

Name of participant: .....

Signature: .....

Name of person taking consent : Mandy J Brimble.

Signature: .....

<b>For researcher use only</b>	
Participant identification code	

### **Further information and contact details**

You may want some more general or specific information about this study. If so please contact me.

Mandy Brimble

Professional Doctorate Student

Cardiff University

School of Healthcare Sciences

College of Biomedical and Life Sciences

Room 2F16 Cardigan House

Heath Park Campus

Heath Park

CF14 4XN

Tel: 02920687701

Email: [brimblemj@cf.ac.uk](mailto:brimblemj@cf.ac.uk)

If you have a concern about any aspect of this study, you should speak to Mandy Brimble, Sally Anstey or Jane Davies and we will do our best to answer your questions. If you wish to express concern to someone not involved in the project, you should contact Dr Kate Button, Director of Research Governance at Cardiff University School of Healthcare Sciences. You can write to Dr Button at the School of Healthcare Sciences, Cardiff University, Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB or contact her by either telephone on 02920 687734 or by Email: [buttonk@cardiff.ac.uk](mailto:buttonk@cardiff.ac.uk)

## Appendix 6: How to complete and send your audio diary



**School of Healthcare Sciences**

**College of Biomedical and Life Sciences**

**Title of Project: Long-term nurse-parent relationships in the children's hospice setting**

**Researcher: Mandy Brimble**

### **How to complete and send your audio diary**

#### **INTRODUCTION**

Thank you for agreeing to complete a series of two audio diaries, outlining your interactions with parents of children you have known for some time. The audio diaries can be completed anytime during a one to three month period. It is probably a good idea to space them out as this should make it easier to manage alongside your work commitments.

For each audio diary please select a parent whom you have known for three years or more and have cared for their child regularly over this period of time, either during short breaks or day care. Please make your recording as soon as possible after the end of the shift spent caring for the selected child and family. As long as the parent meets the criteria outlined at the beginning of this paragraph the selection is entirely up to you. The audio diary recordings can last for up to 30 minutes but do not feel obliged to speak for this length of time. You may wish to speak for only a short while – it's completely up to you.

#### **Completing your audio diary**

Research studies which have used audio diaries have identified that some participants (particularly at the beginning of the project) struggle to start their recording, because they are unsure about what to say. This study is exploring how you manage your long-term professional relationships with parents of children with life-limiting conditions. Therefore there is no set formula. However, these are some **prompts** which **may help you to get you started**.

Please start the recording with your name and first initial e.g. MandyB, followed by the number of the recording, i.e. 1 or 2.

It would be helpful if you could start by telling me how long you have known the child and their family (approximately) and whether they are resident for short break care or attending for day care.

Please tell me the story of the shift in relation to your interactions with the parent(s).

Please include verbal and non-verbal communications.

What were the emotive elements of the communications that took place?

What were the fun elements?

Were there silences?

Did you feel comfortable or uncomfortable at any time and if so why?

If there were no uncomfortable moments, why was this?

Are there times when you feel challenged in terms of personal questions that parents ask you about your own life?

Do you reveal nothing, a little or a lot about yourself during conversations with parents?

Does this vary from parent to parent? If so, why?

Do your relationships with parents in a hospice setting differ from relationships with parents in other clinical settings? If so why?

This is not an exhaustive list. If anything occurs which you think relates to the following factors please include it:

Nature of the speciality

Knowing a parent for a long period of time

The hospice environment

The hospice philosophy of care

Differences from other clinical areas

**Before you start please ensure that you have downloaded WhatsApp to your phone.**



**If you have an iPhone this will be via the App Store**



**If you have an Android phone this will be via Play Store**



**WhatsApp is free. You will need WhatsApp to send the audio recording to me (instructions on how to do this later). Transmitting audio files using WhatsApp is absolutely secure as it offers 'end to end' encryption (for more information see <https://www.whatsapp.com/security/> )**

**The instructions are separated into two sections, one for iPhone users (1) and one for Android phone users (2)**

**I hope that the following instructions for recording and sending your audio diaries are clear. If you have any difficulties please do not hesitate to contact me. Email me at [brimblemj@cf.ac.uk](mailto:brimblemj@cf.ac.uk) and let me know when would be a suitable time to telephone you.**

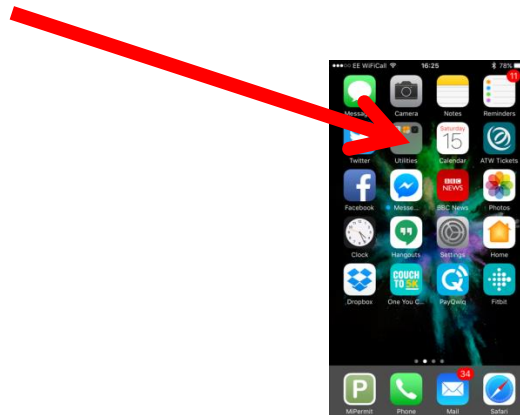
## **SECTION 1 : Making and sending your audio diary using an iPhone.**

**\*If you are using an Android phone, please see later instructions.**

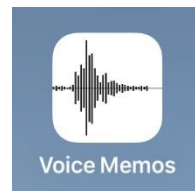
There are two options for using an iPhone to record and send your audio diary. One is to record a Voice Memo and then send it as an attachment via WhatsApp the other is to record and simultaneously send via WhatsApp. I will talk you through the first option then the second.

### **Using an iPhone Option 1: Recording a Voice Memo and then sending via WhatsApp**

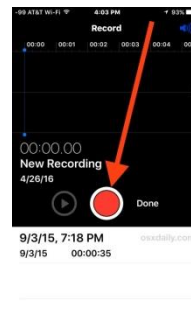
Use the 'Voice memos' function usually located in Utilities, here



1. Open the "Voice Memos" app



2. Tap the red record button to start recording the voice or audio, when finished tap again on the same button to stop recording

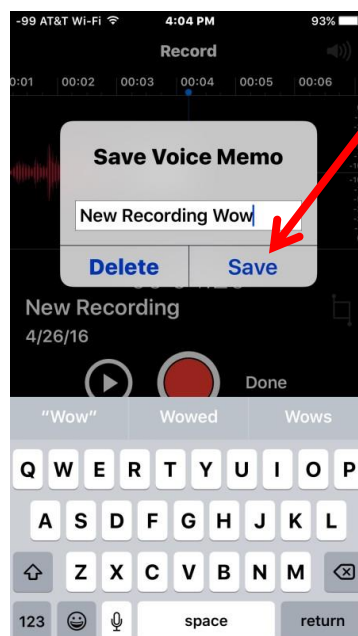


3. When satisfied with the recording, tap “Done”



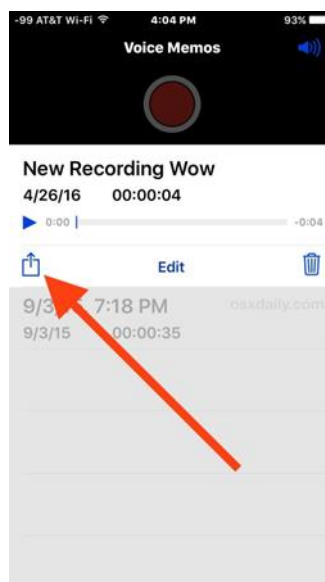
4. Give your recording a name and press the ‘Save’ button. Please use the following naming convention :

Your first name and the first letter of your surname followed by a 1 for your first recording and a 2 for the second, e.g. MandyB1, MandyB2.

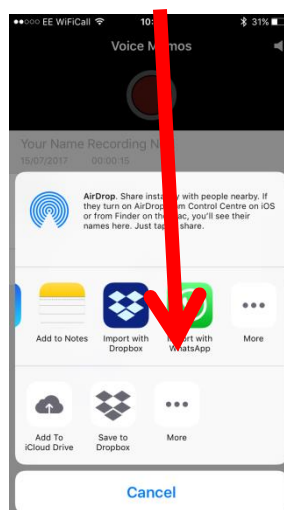


**Sending your audio diary (using an iPhone) \* If you are using an Android phone please see later instructions**

1. Back in the Voice Memos app on iPhone, tap to select on the voice recording you want to send. Then Tap the sharing button, it looks like a box with an arrow flying out of the top.



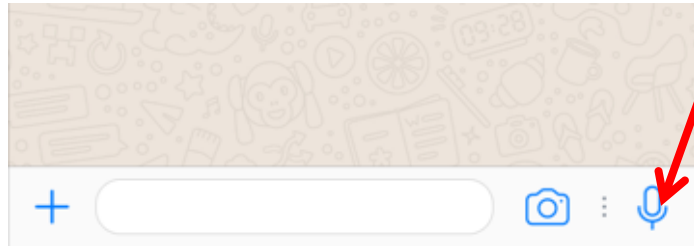
2. Choose the 'Import with WhatsApp' option.



3. Select my name in your contacts list (I will have added you as a contact when you agree to participate in the study).
4. Press 'Send'.
5. Please send me a separate WhatsApp message or email me at [Brimblemj@cf.ac.uk](mailto:Brimblemj@cf.ac.uk) to alert me that you have sent the recording.
6. Please wait for my reply before you delete the original recording from your device. If you choose to retain the recording for your own purposes, e.g. reflection then it is your responsibility to keep it safe and protect the confidentiality of your clients.

**Using and iPhone Option 2 : Using WhatsApp to record and send your audio diary \*\* This option does not allow you to edit the recording before sending\*\***

1. Open WhatsApp and start a 'New Chat'
2. Select my name in your contacts list (I will have added you as a contact when you agreed to participate in the project)
3. At the bottom of the screen you will see a microphone icon



4. Press the microphone icon to record and **keep it pressed down until you have finished recording. Once you stop pressing on the icon the recording will automatically be sent to me.**
5. Please send me a separate WhatsApp message or email me at [Brimblemj@cf.ac.uk](mailto:Brimblemj@cf.ac.uk) to alert me that you have sent the recording.
6. Please wait for my reply before you delete the original recording from your device. If you choose to retain the recording for your own purposes, e.g. reflection then it is your responsibility to keep it safe and protect the confidentiality of your clients.



## **SECTION 2 : Making and sending your audio diary using an Android phone**

There are two options for making and sending recordings with Android. One is to record first and then send this as an attachment or you can record directly into Whatsapp and send it. Both options are absolutely secure as WhatsApp offers 'end to end' encryption.

### **Option 1: Making the recording and sending it as an attachment**

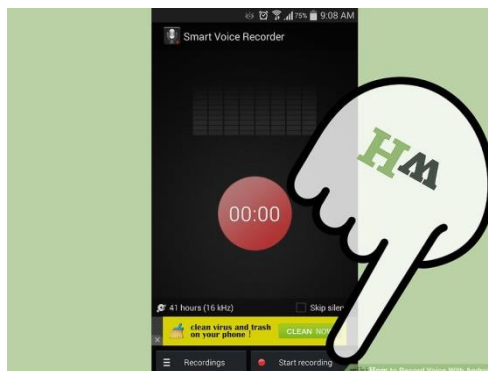
1. Select a free app like "voice recorder" from the options available in the Play Store.



2. Click "install" to install the voice recorder. Click "Open" when you are ready to begin recording.

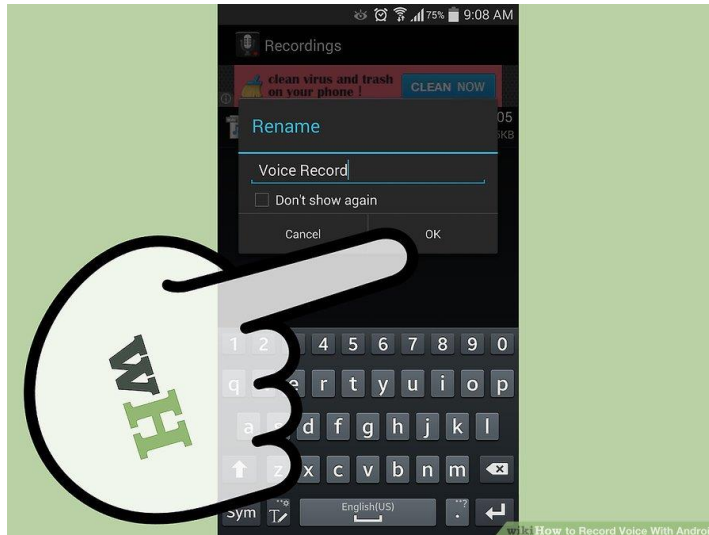


3. Press the "record" button with the red dot to start recording.



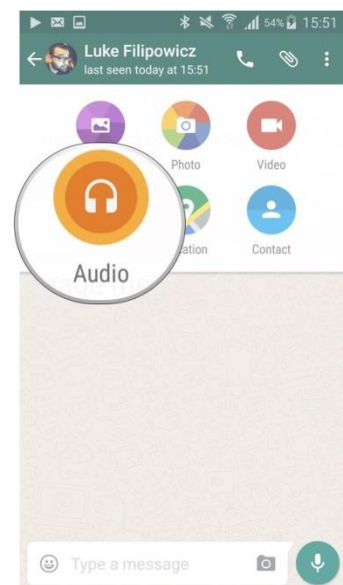
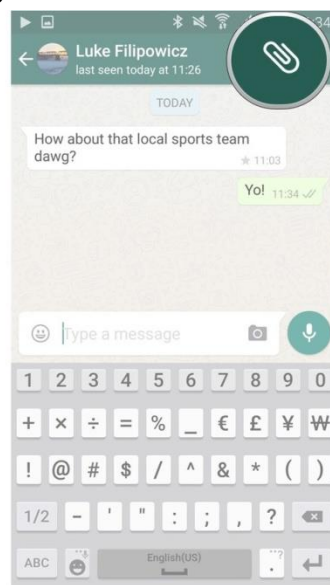
4. Click the red button again to stop recording. Enter a title for your recording and then hit the "save" button to save the file. When saving your recording please use the following naming convention:

Your first name and the first letter of your surname followed by a 1 for your first recording and a 2 for the second, e.g. MandyB1, MandyB2.

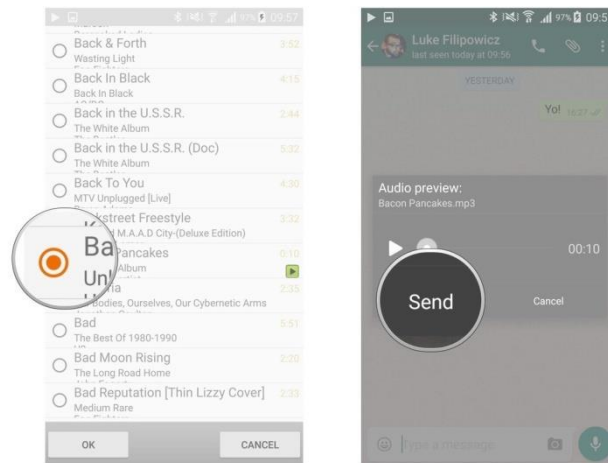


## **Sending the recording using an Android phone**

1. Open WhatsApp, find me in your contacts (I will have added you as a contact when you agree to participate in the study) and tap the attach button (usually a paper clip)
2. Select Audio



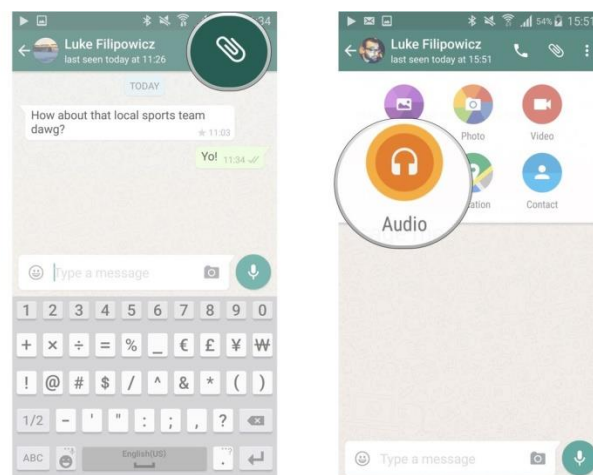
3. Tap choose audio file and select the voice recording you have made.



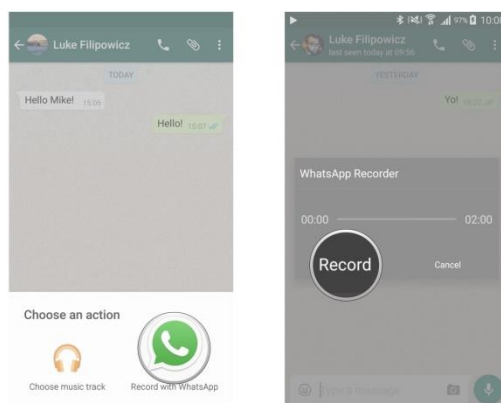
4. Please send me a separate WhatsApp message or email me at [brimblemj@cf.a.cuk](mailto:brimblemj@cf.a.cuk) to alert me that you have sent the recording.
5. Please wait for my reply before you delete the original recording from your device. If you choose to retain the recording for your own purposes, e.g. reflection then it is your responsibility to keep it safe and protect the confidentiality of your clients.

## Option 2: Recording and sending your audio diary solely using WhatsApp

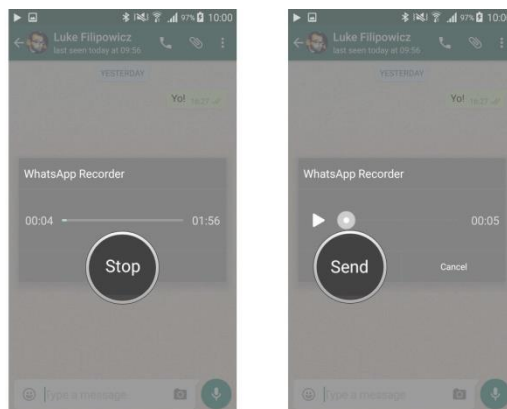
1. Open Whatsapp, find me in your contacts (I will have added you as a contact when you agree to participate in the study), select the attachment button and then the 'Audio' button




2. Tap 'Record with WhatsApp' and select 'Record' to start recording your audio diary.



3. Tap 'Stop' to end the recording and then tap 'Send'



**Appendix 7: Audio diary and telephone interview questionnaire  
(feasibility pilot study only)**

<p><b>School of Healthcare Sciences</b> <b>College of Biomedical and Life Sciences</b></p> <p><b>Title of Project: Long-term nurse-parent relationships in the children's hospice setting</b></p> <p><b>Researcher: Mandy Brimble</b></p> <p><b>Audio diary and telephone interview questionnaire (feasibility pilot study only)</b></p>		
<p>Thank you for agreeing to take part in the pilot study for this project. The information you provide in this questionnaire is really important. It will be used to make changes to the main study, particularly to the guidance for audio diary recordings and their transmission. Your feedback will also be used to make any necessary adjustments to the telephone interviews.</p>	<p><b>Please circle your answer</b></p>	
<p><b>1. Do you usually keep a diary or some kind of record of how you have spent your time or your thoughts/feelings?</b></p>	<p><b>Yes/No</b></p>	
<p><b>2. Did you use a mobile phone to record your audio diary</b> <b>If no, please could you state which equipment was used</b></p>	<p><b>Yes/No</b></p>	
<p><b>3. Was the guidance for recording the audio diary clear?</b> <b>If not, how could it be improved?</b></p>	<p><b>Yes/No</b></p>	
<p><b>4. Were the instructions for transmitting the audio diary to me clear?</b> <b>If not, how could they be improved?</b></p>	<p><b>Yes/No</b></p>	
<p><b>5. Was it easy to record your thoughts and feelings in the form of an audio diary?</b></p>	<p><b>Yes/No</b></p>	

<p>If no, please could you say why this was difficult for you and what would have made it easier (if anything)</p>	
<p>6. Was it difficult to find the time to make the audio recording?</p>	<p>Yes/No</p>
<p>7. How soon after your shift did you make the audio recording (Please circle the appropriate response)</p> <p>a) Immediately  b) 1-2 hours  c) 2-4 hours  d) 4-8 hours  e) Day after  f) More than a day after</p>	
<p>8. Was it difficult to find a private space to record your audio diary?</p>	<p>Yes/No</p>
<p>9. Where did you usually record your audio diary? (Please circle the appropriate response)</p> <p>a) At work  b) In the car on the way home from work  c) At home  d) Other (please specify)</p>	
<p>10. Did you find this method of data collection intrusive?</p>	<p>Yes/No</p>
<p>11. Did knowing that I would be listening to your audio diary alter the content?</p>	<p>Yes/No</p>
<p>12. Is there anything you didn't include?</p> <p>If yes, what (if anything) would encourage you to include the matters you chose to leave out?</p>	<p>Yes/No</p>
<p>13. Were the audio diary recordings useful in helping you to reflect on your practice?</p>	<p>Yes/No</p>
<p>14. Have you or will you use any of these reflections to meet the NMC revalidation requirements?</p>	<p>Yes/No</p>

<p><b>15. Were there any problems with transferring the audio diary to me?</b></p> <p>If yes, what were they?</p>	<p><b>Yes/No</b></p>
<p><b>16. What did you like best about recording an audio diary?</b></p>	
<p><b>17. What did you like least about recording an audio diary?</b></p>	
<p><b>18. Were the telephone interviews a useful way of enabling you to provide a more in-depth explanation of your audio diary recordings</b></p>	<p><b>Yes/No</b></p>
<p><b>19. Were the telephone interviews useful in helping you to reflect on your practice?</b></p>	<p><b>Yes/No</b></p>
<p><b>20. Would you have preferred to be interviewed face to face</b></p>	<p><b>Yes/No</b></p>
<p><b>21. Please explain the reasons for your response to Q20 above</b></p>	
<p><b>22. Is there any other feedback you would like to give about the methods used to collect data in this pilot study?</b></p>	
<p><b>Thank you for completing this questionnaire.</b></p>	

## Appendix 8: Comparison of two narrative analysis models

I analysed the passage below from the first audio diary received from my first study participant Alex. I firstly used Labov's structural model (1972) and secondly Riessman's Thematic model (2008)

*Shane found it very hard to say any words. He sat on a chair, tears flowing down his cheeks, shaking. I wasn't really sure what to do but it felt appropriate to put my hand firmly on his shoulder. It's harder to know if touch is an appropriate means of communication especially when you're talking to someone of the opposite sex. However, I just went with my gut feeling in that moment. We were just quiet for some time. I'm not really sure how long that amount of time was but eventually Shane felt able to say that (recounts details of chaotic domestic situation). Shane was shaking and it was quite emotional watching him umm (pauses) and I felt my own eyes 'well up' a bit, not that I expressed that (participant sounds emotional) overtly but I was aware that I was feeling emotional too. He spoke of (more information about domestic situation- redacted). That felt like quite a shocking thing to hear. He cried (pauses) saying (further details about his fears for the relationship between him and the mother of the child – redacted). As a nurse, part of you thinks, no matter what the situation, something's programmed within you to want to try and make things better for people, even when you can't and I felt myself wanting to say something to make it better.*

*I don't really give anything of myself, I don't think directly to Shane and Bride during the shift, of my own personal thoughts, of my own person but I think that some of the care that I give perhaps is influenced by some of my personal experiences. My own sister umm died a few years ago in a hospice and I sometimes find, felt, felt that, at the time, that I wasn't always listened to and that sometimes there weren't honest conversations and clear conversations and that sometimes I needed people to go over things again with me, to help me to take in information when my world felt like it was bursting and when I saw Shane, I know it's a completely different situation, but seeing him in that emotional state it reminded me of that feeling of, feeling like you are going to burst coz you've got something that's hurting you so much inside and it just needs to come out in a safe way and that after you've got rid of all of that you can start to see how you can function again. So perhaps part of me, my own personal experience, was in the care that I'd given but I would never feel or there was not the need or the want, nor my want to share any of that information with him.*



## Labov's structural model (1972) taken verbatim from Esin (2011)

### Brief explanation of model

Labov (1972) developed his model on the assumption that stories of events contain narrative clauses. These clauses have a beginning, a middle and an end. But there are other elements of narrative structure found in more fully developed narrative clauses. He developed a six-part model to be used in analysing the structure of narratives (Table 5.4).

**Table 5.4** The elements of story text in Labov's model

1. Abstract (A):	There are one or two clauses that summarise the story When the whole story is heard it can be seen that the abstract does encapsulate the point of the story
2. Orientation (O):	Orientation clauses function to provide a setting in which the events of the story are told
3. Complicating action (CA):	Complicating action clauses relate the events of the story These clauses usually represent time in a linear way with a chronological order following the 'then, and then' structure They may relate a series of events
4. Result (R):	These are the clauses that tell the listener how the story ends
5. Evaluation (E):	The evaluation clauses present the narrator's perspective on the events They mediate the 'point' of the story Labov (1972) identifies three main types of evaluation in story texts: 1. <i>External</i> : these are the clauses in which the narrator steps outside the complicating action and tells the listener the point 2. <i>Embedded</i> : these are the clauses in which the narrator tells the listener how they felt at the time, without interrupting the flow of the story 3. <i>Evaluative</i> : these clauses report actions that reveal emotions as a part of the story
6. Coda (C):	These clauses link the past world of the story to the present world of the storytelling They function 'to "sign off" the story and offer the floor to the listener' (Patterson, 2008: 27)

Analysts can use the 'question method' for the categorisation of clauses in narrative that can be assigned to one element in Labov's model. This is based on the idea that narratives provide a series of answers to the underlying questions that all narratives address. Thus the function of clauses in narratives is to answer different questions (Patterson, 2008). Table 5.5. shows the questions that could be used to identify each element in a story.

**Table 5.5** Questions that could be used to identify each element in a story

Elements	Questions
Abstract	What was this about?
Orientation	Who is the story about, when did it happen, What happened, where did it happen?
Complicating action	Then what happened?
Evaluation	So what?
Result	What finally happened?
Coda	This element does not answer any particular question It functions to sign off the narrative as it returns to the present time of the telling

### Answering the questions for each element

#### **Abstract** – What was this about?

A children's hospice nurse's interaction with a distressed parent of a child with a life-limiting condition.

#### **Orientation** – What is the story about, when did it happen? What happened, where did it happen?

The story is about how a nurse supported a distressed father at the end of the child's short break care stay at the hospice. The father was distressed about domestic conflict at home within the chaotic family situation. The nurse took the father to a space away from the communal hospice area to offer some privacy.

#### **Complicating action** – Then what happened?

The distressed father was able to talk to the nurse as well as take some time to be silent. The nurse recounted the instinctive use of therapeutic touch, whilst acknowledging that it is difficult to know whether to touch a parent or not, especially one of the opposite sex.

The nurse felt emotional watching the father and felt her own eyes fill with tears. She points out that she didn't verbally express this emotion. She sounds emotional when recounting this part of the story.

#### **Evaluation** – So What?

The nurse uses private space, verbal communication, silence and therapeutic touch to support the father.

She is impacted emotionally by his distress.

She is conscious of a desire to make things better even when there is nothing she can do.

**Result** – What finally happened?

The nurse reports feeling shocked by some of what the father tells her.

She acknowledges that she is emotionally impacted by the situation but is careful not to verbalise this and the father doesn't notice as he is not looking at her.

She acknowledges her innate programming (as a nurse and a human being) to want to try to make things better, even when she knows she can't.

**Coda** – 'signs off' the narrative as it returns to the present time of the telling.

The nurse reflects and concludes that she does not give much of herself (despite recounting feeling emotional and becoming tearful both then and when telling her story) or reveal anything of herself during the interaction. She does state that her past personal experience helps her to understand how the father is feeling and the depth of the emotion. She says that this influences the care that she gives. However, she stresses that she would never need or want to share her own experience with the father.

Emerging codes

Careful use of therapeutic touch

Silence and verbal communication

Father's distress impacts emotionally on the nurse

Keeping something back (?self preservation)

Avoiding personal disclosure (?professional boundaries)

Nurses innate desire to make thing better (whilst knowing that she can't)

**Riessman's Thematic model (2008) taken verbatim from Esin (2011)**

This model focuses on the content of a narrative; 'what' is said more than 'how' it is said, the 'told' rather than the aspects of 'telling' (Riessman, 2008). The content of the told story is at the centre of thematic analysis. There is minimal attention to structures selected by the narrator to tell her/his story, function or contextual details of the stories. The thematic model can be applied to a wide range of narrative text, including narratives produced in interviews and written documents.

The analyst can start the thematic analysis by the open coding of data. This means building a set of themes by looking for patterns and meaning produced in the data, labelling and grouping them in connection with the theoretical framework of the research.

**Table 5.7** Four stages in the application of the thematic model

<b>1. Selection of the subtext/segments</b>
All the relevant sections of the transcript relevant to the research question are marked and assembled to create a new file or subtext. For example, if the research question involves healthcare, all the sections about various aspects of healthcare should be marked for analysis. Usually the selected subtexts are treated independently from the total context of the narrative. However, in practice, narrative researchers include contextual details in their interpretation (see Riley & Hawe, 2005; Phoenix & Sparkes, 2008).
<b>2. Definition of thematic categories</b>
Themes or perspectives are identified across the selected subtext. These can be in the form of words, sentences or groups of sentences. These categories can be predefined by the theory. Another method can be reading the selected subtexts multiple times and defining the themes that emerge from these readings. There is no limit to the number or form of thematic categories. The decisions on the number of categories depend on the analyst's perspective. Some analysts work with many, subtle categories that retain the richness of the narrative, which will require meticulous work on the identification and analysis of categories. Some analysts, on the other hand, work with a small number of broad categories, which require less work.
<b>3. Sorting the material into categories</b>
Separate sentences and utterances across the narrative texts are assigned to relevant categories. In this way, different parts of narratives will be grouped under the defined thematic categories.
<b>4. Drawing conclusions</b>
The narrative content collected in each thematic category can be used to describe the meanings in the content of the narrative text.

Stage 1: Editing of the text to remove all content not relevant to the research question.

~~Shane found it very hard to say any words. He sat on a chair, tears flowing down his cheeks, shaking. I wasn't really sure what to do but it felt appropriate to put my hand firmly on his shoulder. It's harder to know if touch is an appropriate means of communication especially when you're talking to someone of the opposite sex. However, I just went with my gut feeling in that moment. We were just quiet for some time. I'm not really sure how long that amount of time was but eventually Shane felt able to say that (recounts details of chaotic domestic situation). Shane was shaking and it was quite emotional watching him umm (pauses) and I felt my own eyes 'well up' a bit, not that I expressed that (participant sounds emotional) overtly but I was aware that I was feeling emotional too. He spoke of (more information about domestic situation- redacted). That felt like quite a shocking thing to hear.~~

~~He cried (pauses) saying (further details about his fears for the relationship between him and the mother of the child—redacted).~~ As a nurse, part of you thinks, no matter what the situation, something's programmed within you to want to try and make things better for people, even when you can't and I felt myself wanting to say something to make it better.

*I don't really give anything of myself, I don't think directly to Shane and Bridie during the shift, of my own personal thoughts, of my own person but I think that some of the care that I give perhaps is influenced by some of my personal experiences. My own sister umm died a few years ago in a hospice and I sometimes find, felt, felt that, at the time, that I wasn't always listened to and that sometimes there weren't honest conversations and clear conversations and that sometimes I needed people to go over things again with me, to help me to take in information when my world felt like it was bursting and when I saw Shane, I know it's a completely different situation, but seeing him in that emotional state it reminded me of that feeling of, feeling like you are going to burst coz you've got something that's hurting you so much inside and it just needs to come out in a safe way and that after you've got rid of all of that you can start to see how you can function again. So perhaps part of me, my own personal experience, was in the care that I'd given but I would never feel or there was not the need or the want, nor my want to share any of that information with him.*

#### Stage 2: Definition of thematic categories

I didn't use a framework for this I just read and re-read it and arrived at some categories that I felt emerged from this extract.

Physical interaction

Communication

Emotional response

Holding back

Personal influences

Boundaries

#### Stage 3: Sorting the material into categories

##### **Physical interaction**

*I wasn't really sure what to do but it felt appropriate to put my hand firmly on his shoulder. It's harder to know if touch is an appropriate means of communication especially when you're talking to someone of the opposite sex. However, I just went with my gut feeling in that moment*

##### **Communication**

*We were just quiet for some time.*

**Emotional response**

*P was shaking and it was quite emotional watching him umm (pauses) and I felt my own eyes 'well up' a bit,*

*I was aware that I was feeling emotional too.*

*As a nurse, part of you thinks, no matter what the situation, something's programmed within you to want to try and make things better for people, even when you can't and I felt myself wanting to say something to make it better.*

**Holding back**

*not that I expressed that (participant sounds emotional) overtly*

*I don't really give anything of myself, I don't think directly to P and B during the shift, of my own personal thoughts, of my own person*

**Personal influences**

*I think that some of the care that I give perhaps is influenced by some of my personal experiences. My own sister umm died a few years ago in a hospice and I sometimes find, felt, felt that, at the time, that I wasn't always listened to and that sometimes there weren't honest conversations and clear conversations and that sometimes I needed people to go over things again with me, to help me to take in information when my world felt like it was bursting*

*I know it's a completely different situation, but seeing him in that emotional state it reminded me of that feeling of, feeling like you are going to burst coz you've got something that's hurting you so much inside and it just needs to come out in a safe way and that after you've got rid of all of that you can start to see how you can function again.*

*So perhaps part of me, my own personal experience, was in the care that I'd given*

**Boundaries**

*I would never feel or there was not the need or the want, nor my want to share any of that information with him.*

**Stage 4: Drawing conclusions**

In this extract the nurse is emotionally affected by the father's distress but points out that she would not express this to him, demonstrating that she holds back her emotions. Silence is used to help the father gather his thoughts. The nurse also instinctively uses therapeutic touch, although she is aware that this needs to be carefully considered. There are contradictions in the nurse's thoughts about the care that she gives, initially saying that she holds back and doesn't give of her own person but later revealing quite a lot of detail about her own closely related experiences and acknowledging that

this influenced her care practices. She is very clear that there was no need or indeed any desire on her part to share her personal experiences with the father, suggesting that she has clear boundaries about sharing personal information. The nurse's description of the interaction suggests that personal factors and professional considerations are being constantly juggled to achieve a balanced approach.

## Appendix 9: Braun & Clarke (2006) Phases of Thematic Analysis

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic “map” of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

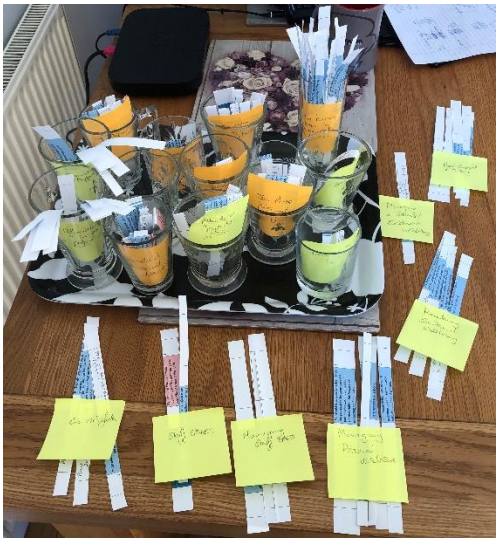


**Braun and Clarke (2006) 15-Point Checklist of Criteria for Good Thematic Analysis**

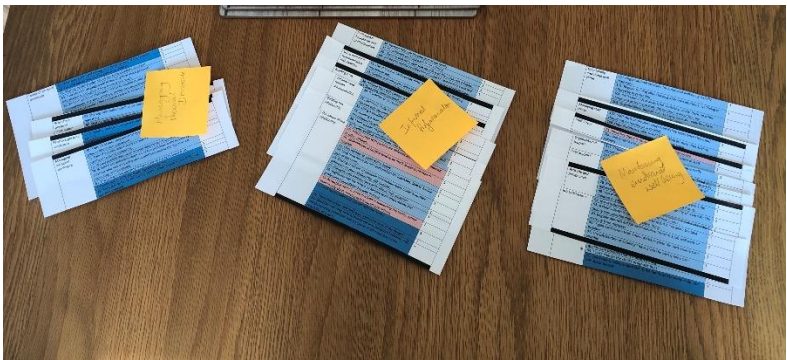
Process	No	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for “accuracy”.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do and what you show you have done – i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as <i>active</i> in the research process; themes do not just “emerge”.

**Appendix 10: Identifying Categories and Early Themes**  
**PATRICK**

Categories

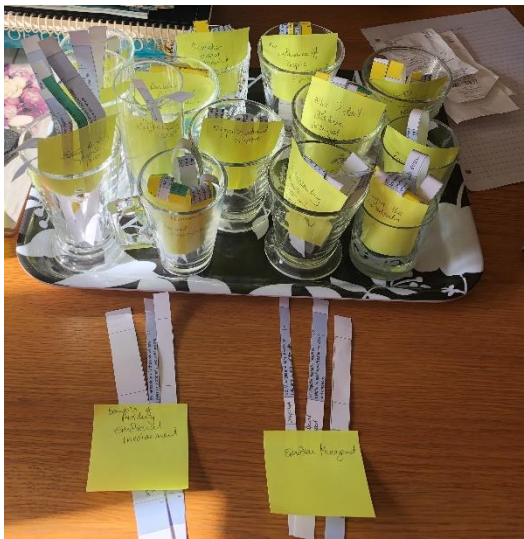


Early themes

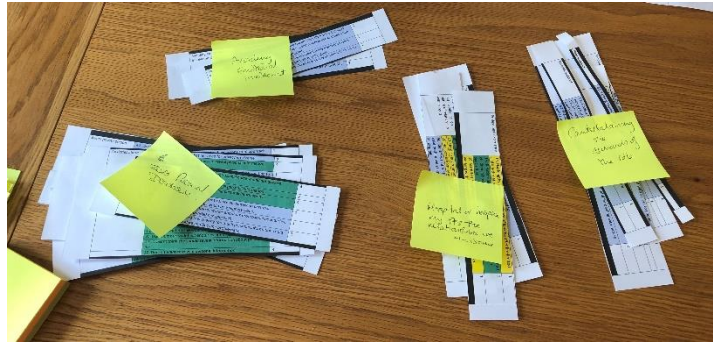


**LES**

Categories



Early themes

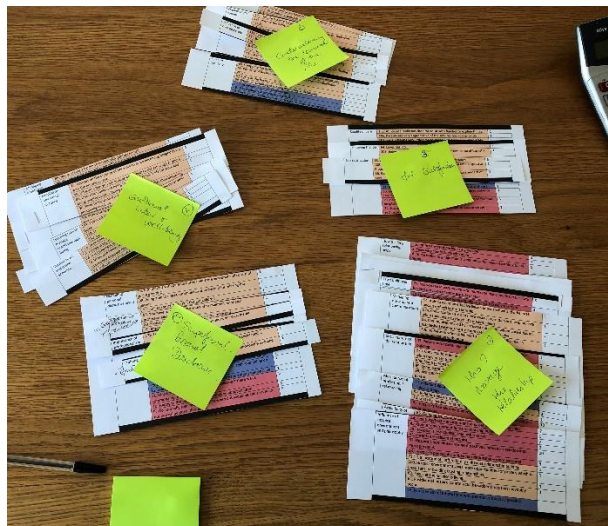


JO

Categories



Early themes



## **Appendix 11: Key to Pseudonyms**

### **Participant 1 Audio diary and telephone interview 1:**

Nurse – Alex

Stepfather – Shane

Child – Bridie

### **Participant 1 Audio diary and telephone interview 2**

Nurse – Alex

Mother - Sonia

Child - Kayleigh

Adult sibling - Trudy

### **Participant 2 Audio diary and telephone interview 1**

Nurse – Chris

Young Man – Charles

Mother - Sarah

### **Participant 3 Audio diary and telephone interview 1**

Nurse – Les

Mother – Verity

Child – Mitch

Dad - Graham

### **Participant 4 Audio diary and telephone interview 1**

Nurse – Jo

Young Person – Andy

Mother – Hayley

Father - John

### **Participant 5 Audio diary and telephone 1**

Nurse – Ashley

Young Person – Joe

Mother – Sandra

Father - Mike

**Participant 5 Audio diary and telephone 2**

Nurse – Ashley

Mum – Anne

Dad – Doug

Brother – Rory

Child - Max

**Participant 6 Audio diary and telephone interview 1**

Nurse – Patrick

Child – Bryan

Mother – Judith

Sister – Evie

Grandmother - Nanny

**Participant 6 Audio diary and telephone interview 2**

Nurse- Patrick

Child – Carl

Mother – Joan

Step-Dad – Harry

Step-Son (Harry's son) – Simon

Half-sister - Maddy



## Appendix 12: Welcome to Holland



### WELCOME TO HOLLAND

by  
Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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### **Appendix 13: Identifying a theory**

EI was a theory that had occurred to me whilst I was writing up the individual analysis as so many of the strategies the participants' employed were suggestive of facets of EI models, e.g. empathy and self-regulation. Furthermore, since my research question was focused on emotional labour and professional integrity and EI has been found to be a mediator of emotional labour and job stress in nursing (Karimi et al. 2013; Hong and Lee 2016, Vahidi et al. 2016), a component of nursing professionalism (Kooker et al. 2007) and linked to professional integrity (Mesmer-Magnus et al. 2008) it seemed a pertinent and useful way of theorising the findings. However, it felt just a little too convenient that the first theory that occurred to me would be the one that I eventually utilised in the discussion chapter. So, alongside work on the Whole Group Analysis I explored other theoretical frameworks such as Interpersonal Relations (Peplau 1988b), Self Determination (Ryan and Deci 2000), Functional Attitude (Katz 1960), Planned behaviour (Ajzen 1991) and a nursing professional values model. (Kaya and Boz 2019). However, I found that none really allowed me to fully explore the themes identified in Chapter 5 or apply them to hospice nursing practice in a meaningful way. Self Determination theory was probably the closest. This theory differentiates between autonomous and controlled motivation (on a continuum) and the effects of extrinsic rewards on intrinsic motivation (Ryan and Deci 2000). Some aspects of this theory could be applied to some of my findings, particularly by using the mini theories which include the influence of environment, psychological needs, self-regulation and well-being on performance. However, the framework focuses on factors which enhance or undermine different types of motivation and since I wanted to explore strategies for managing relationships rather than the factors which motivated the participants to act in a certain way then it was not suitable. However, if one wanted to revisit my transcripts and probe motivation via further interviews then Self Determination theory would be a useful means of informing an interview schedule and subsequent analysis. Therefore, I would suggest that it may be more suitable for deductive rather than inductive research.

Nonetheless, I remained resistant to returning to EI and started to wonder if I had, in fact, 'labelled' the strategies described by the participants in a specific way because EI was in my sub-conscious. I really wanted the theory used in this discussion to arise from the findings rather than vice-versa, so I returned to the transcripts, my initial thoughts, coding and categorisation to check that I had been true to the participant voices and that the participant voices really had informed the choice of theory. This did seem drastic, particularly as I had carried out these steps many times during my analysis. Nevertheless, such was my resistance to taking what I had come to view as the easy option, that I spent a lot of time procrastinating before finally returning to EI theory. It may be that a study that set out to explore emotional labour would inevitably lead to a theory involving emotion. However, there were other facets to the research question and aims so I had not expected one theory to encompass all the findings. Indeed, although many components of EI theory link with the internal strategies employed by the participants, the other more external factors, i.e. job satisfaction, positivity and fun and extraordinary peer support initially appeared to sit outside the EI framework. So, I decided to set these aside in the first instance whilst I explored EI further; thinking that perhaps I would find another theory from which to construct a hybrid. However, exploration of EI research led me to numerous studies which had identified that these factors positively correlate with, contribute to, or are influenced by EI.