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**A QUALITATIVE EXPLORATION INTO THE
IMPACT THAT WORKING AS A NURSE IN A
CHILDREN'S HOSPICE HAS UPON ONE'S
THOUGHTS AND FEELINGS SURROUNDING
PERSONAL MORTALITY.**

Catherine Sarah Rose Livesey

Dissertation submitted to the University of Chester for the Degree
of Master of Arts (Clinical Counselling) in part fulfilment of the
Modular Programme in Clinical Counselling.

November 2014

Abstract

This research study explores four nurse's experiences of working in a children's hospice and uncovers hospice experiences that contribute to personal mortality exploration. The study investigates how these experiences impact the nurses' thoughts and feelings surrounding their comprehension of their own life and death. The study addresses if a counselling service would be viewed as a beneficial resource in supporting hospice nurses explore their mortality, and where appropriate, also offers recommendations for additional emotional support for nurses. The study is qualitative in nature and uses Interpretative Phenomenological Analysis (IPA) as its mode of inquiry and analysis. Following interviews, transcription took place before carrying out a detailed analysis of the data.

The study revealed that the nurses hold extensive knowledge in their field of work and possess a considerable appreciation of their own mortality. However, there was a clear avoidance for most of the participants in discussing personal mortality in any significant emotional depth. A reoccurring link was discovered between being a children's hospice nurse and the mortality of the nurses' own children. This link proved to provoke the most significant emotional response within the nurses. Finally the research found that children's hospice nurses would find a staff counselling service beneficial to support them in their role.

The study concludes that further research into the link between children's hospice nursing and personal mortality wishes would be helpful in creating a solid body of literature within this field. It is also suggested that research with hospice nurses who have been witness to what they perceive as 'traumatic' experiences and whom have engaged in counselling as a result of these traumas may be another area worthy of research.

Declaration

The work is original and has not been submitted previously in support of any other qualification or course.

Signed:

Date: 26th November 2014

CSR Livesey

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List of Abbreviations

BACP – British Association for Counselling and Psychotherapy

CH – Children’s Hospice

CHN – Children’s Hospice Nurse

IPA – Interpretive Phenomenological Analysis

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Fig.1 Table of master themes identified by cross sample

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CHAPTER 1: INTRODUCTION

1.1 Background

"Love and steel, how kind. Anyone doing hospice work will need plenty of both." ¹

In 1967, Dame Cicely Saunders founded St Christopher's Hospice. This marked the turn of the modern hospice movement. Saunders revolutionised the way that society cared for the ill, dying and bereaved, transforming the discipline and culture of palliative care. Saunders was passionate in ensuring that patients not only received excellent medical and nursing care, but also received practical, emotional, social and spiritual support. This was not only deemed as necessary support for the patients but also deemed as necessary support for close relatives. Saunders (1996) referred to this new concept as 'total care'. Saunders is regarded as a pioneer in the field of palliative care and due to her contemporary vision today there are forty nine CH services in the United Kingdom (Middleton, 2013). All of these CHs offer specialist palliative care services to children and young people with life threatening and life limiting conditions and their families. The philosophy of care throughout CHs remains the same as Saunders vision 50 years ago. They take a holistic approach to enhance the quality of life of these children and young people and their families (Claire House, 2013; Derian House, 2013; Hope House, 2013).

¹ Dame Cicely Saunders was reputed to have made this comment in response to a viewer who observed a look of 'love' and 'steel' in Cicely's portrait which at the time was displayed in the National Portrait Gallery. (<http://www.churchtimes.co.uk/articles/2006/17-march/gazette/recollection-%E2%80%98you-matter-because-you-are-you%E2%80%99, n.d.>).

Having provided a background to the hospice movement and explained the concept of a CH, I would like to refer back to the opening comment made by Saunders to explain its significance in my research. I found Saunders' comment when researching into the history of the hospice movement, and I was instantly drawn to the reputed comment. On the surface the comment is beautifully simple, but as I began to explore the concept of 'love' and 'steel' in greater depth an evolving complexity emerged. Two interpretations of this comment resonate deep within me and it is due to these interpretations that I find the comment so poignant. The first level resonates on the literal interpretation of the quote as Dame Cicely Saunders aimed to convey. This being the perceived personal attributes that enable individuals to work in a hospice environment such as, 'love' – (caring, compassion, warmth) and 'steel' – (strength, solidness, hardiness and boundaries). My second interpretation of this quote speaks to me from a deep existential perspective. 'Love' to me is fluid and active and it oozes a sense of life and living. In contrast 'steel' evokes a cold, dark, heavy inalterability, and to me is interpreted as symbolic of death and dying. My long standing experience in the field of CHs has led me to literally see, touch, hear and smell 'love' and 'steel'; or 'life' and 'death'. It is being privy to these experiences that has made me or perhaps 'enabled' me to begin to search for meaning in my own life and death. Often I would (and still do) go home after a day at work wondering, searching, seeking an answer to such a question as, is there a heaven? What is the body? What is the soul? Is there such a thing as a spirit? What is life, and what does it mean to be alive? My experiences have given rise to practical considerations and wishes. Seeing a young person the same age as me lying on a bed in a cold room was scary, sad, bizarre, intriguing and surreal. Discussing with parents what they wish their daughter to be dressed in for her funeral led me to consider how I wish to

be dressed for my funeral. Visiting funeral directors and witnessing dignified and respectful care of the deceased through to witnessing poorer standards of care, enabled me go home and tell my husband my preferred choice of funeral director. These are just a small handful of examples of the impact working in a CH has had upon my thoughts and feelings surrounding my mortality.

1.2 Research Focus

The focus of my study is to explore exactly how working in a CH impacts nurse's thoughts and feelings about their own mortality. The rationale for this study emerges from the significant gap in qualitative research surrounding the exploration of authentic experiences of nurses which may be significantly influential when questioning personal mortality (Wilson & Kirshbaum, 2011; Froggatt, 1998 and DeArmond, 2013). The research that has been conducted in this area has been quantitative in nature, is not UK based, and is not specific to CH caregivers. Without adequate and appropriate research into the authentic lived-experience which includes exploration of ones thoughts and feelings surrounding personal mortality, how can hospices be sure they are providing the best support to assist nurses on their personal journey of mortality? It is therefore within this realm that inspired research focus and the following question derived:

'What impact does working as a nurse in a children's hospice have upon one's thoughts and feelings surrounding personal mortality?

1.3 Overall Research Aims

The aim of this research is to explore the depth to which nurses contemplate personal mortality. I hope to achieve this through the following objectives:

- Identify specific experiences within the hospice that trigger personal mortality exploration.
- Explore the depth of personal thoughts and feelings surrounding one's own mortality in relation to these experiences.
- Establish if counselling would be viewed as a beneficial resource in supporting nurses.
- Where appropriate, make recommendations based on the findings and suggest further research topics within this area.

1.4 Value of this Research

There are a number of benefits to this research. Hospice staff members will be given a voice as to the emotional demands of their role, which will further inform hospices and other similar organisations how working in the field of death and dying impacts care staff. I aim to raise the profile of counselling within hospices by considering if a staff counselling service would be beneficial in CHs. If staff can explore their mortality then there is also evidence to suggest that the quality of care that staff provide clients will be enhanced (Peters, Cant, Payne, O'Connor, McDermott, Hood, Morphet, Shimoinaba; 2013, McNamara, Waddell, Colvin; 1995; Whittle, 2002). On a personal level, this research will allow me to further explore my own issues surrounding mortality and how this affects my personal and professional life.

1.5 Structure of the Dissertation

This introduction has provided a background and focus to my research, stating the aims and value of the study. Chapter Two, the literature review, will analyse and critically explore existing research in my chosen area of study. Chapter Three introduces my research question followed by my philosophical perspective and subsequent research design decisions. Chapter Three also focuses on methods of data collection, analysis, validity and ethical considerations. In Chapter Four, I will present my findings, and in Chapter Five discussions around these findings will be explored along with my conclusion, recommendations and areas requiring further research.

CHAPTER 2: LITERATURE REVIEW

2:1 Introduction

The aim of this chapter is to review any literature connected to my research focus. This provides valid evidence that my research question is one that is worthy of researching (Biggam 2008; Moustakas, 1994). As previously established, the design of my research is phenomenological in nature and qualitative in its approach. In keeping with this design, my literature review will also be phenomenological in nature. Randolph (2009) explains that in order to achieve a phenomenological literature review, five steps need to be taken; Bracketing, collecting the data, identifying meaningful data, giving meaning and the final stage creation of a thick and rich description of the phenomena as I experienced it.

As an experienced hospice caregiver I recognised the importance of 'bracketing' off my experiences and not allowing them to influence or bias my reading and evaluation. Another aspect of validity to remain mindful of was that the majority of searches were conducted prior to conducting my interviews due to the timescale of the study. Rawson (2006) argues that a literature review prior to interviews can lead researchers to be at risk of tunnel vision. This view provided another motive to ensure I remained vigilant in addressing and reviewing my ability to bracket off my experience throughout this review. To 'collect my data' I created a list of keywords that had relevance to my research focus (See Appendix 1). I then used a range of databases to search for literature. The databases included, CINAHL, PSYArticles, PubMed, Wiley Online Library, Google Scholar, The University of Chester Catalogue

and Edge Hill University Catalogue. A snowballing process evolved through these databases.

To 'identifying meaningful data' the process was to read the literature, highlight the meaningful and relevant data and then record this in a card index format for easy access and management (McLeod, 2003; Randolph, 2009). Please see Appendix 2. To 'give meaning' to the literature was the next process I undertook and this was achieved through putting the meaningful statements into categories and then sub-headings. I recognised at this stage the wide ranging areas that are relevant to my research focus. All would be valid areas to present in this literature review but due to the small scale nature of this dissertation, I have selected four areas which feel most pertinent to my research focus.

2:2 The Death of a Child

"Children are not supposed to die, but they do." (Armstrong-Dailey, 2000, x)

The death of a child is recognised in research literature as being the hardest, most painful and difficult loss to deal with and accept (Foxall, 2005; Hindmarch 2003). The death of a child is described as catastrophic, unfair and unjust (Foxhall, 2005). Childhood is expected to be a time of fun, growth, learning and living and the child is expected to outlive the lives of his/her parents. A parent never imagines they will be burying their child (Aiken, 2000; Foxhall, 2003; Wiersbe, 2011). Aiken comments that "Death is seen as a more appropriate companion of old age than of childhood" (2000, p.224). The grief a parent experiences following the death of a child is described as a unique pain which is both physically and emotionally wrenching and

disabling (Hindmarch, 2003; Wiersbe, 2011). Hill (1994) and Hindmarch (2003) explain that those who were nearest to the child will feel the devastating impact of the child's death the strongest whilst also recognising that the death will affect far more people than just the immediate family members. Hill (1994) explains that carers and nurses over time build up special and supportive relationships with the child and acknowledges that they too will experience grief following the child's death. Hindmarch (2003, p.5) explains that for medical and nursing staff "...there is a special sense of failure and frustration when a child dies". Indeed this may be true, but a sense of relief and success may also be experienced by professionals following the death of a child. The feelings and emotions attached to a child's death will be dependent on a number of different factors, such as the individual child's situation, the cause of death, the skills and the personality of the professional staff looking after the child for example (Hindmarch, 2003). In addition to these factors such as personal resilience, identification with the dying child and past personal bereavements should also be considered when looking at how a healthcare provider copes with a specific child's death. Hopkinson, Hallet and Luker (2005) and Van Hooft, (2003 as cited in Tschudin) comment that professional boundaries enable nurses to protect themselves from the emotional labour of a dying or deceased child. However it could be argued that professional boundaries can create a barrier to the natural grieving process for healthcare providers. Anderson, Ewen & Miles (2010) and Brosche (2007) discuss how nurses and healthcare providers may feel the need to grieve, but due to professional expectations are inhibited. Anderson, Ewen & Miles (2010) and Brosche (2007) continue to explain that this grief is sometimes not recognised by or ignored by others. It could therefore be suggested that nurses are at risk of becoming disenfranchised grievers.

Hindmarch explains that “Whether personally or professionally involved, the death of a child is seen as the most difficult loss to cope with” (2003, p.30). Talbot, (2002) Wheeler (2001) Neimyer, Prigerson & Davies (2002) Hindmarch (2009) and Morgan (2009) all explain that the death of a child presents a painful suffering that challenges the bereaved in making sense of the death and finding meaning in the phenomena. This existential crisis or predicament tests our belief systems and challenges our motives in life (Neimyer, 2002; Hindmarch, 2009). This is described as a normal reaction to the death of a child and represents a part of the grieving process.

2:3 Nursing the Dying

“The everyday practice of health professionals involves being close up to human existence in the raw. In such closeness, raw life is there before us without mitigation, the vulnerability of human flesh exposed, the radical uncertainty of our lives laid bare. Sometimes the inevitability of death – our impending doom – is starkly present...” (Austin, Brintnell, Goble, Kage, Kreitzer, Larsen, Leier, 2013, p.76)

In order to enter the world of a nurse caring for the dying, it seems appropriate to explore what the term ‘dying’ means. From a physiological perspective, Longaker, (1997) and Aiken (2000) explain that death is a process of irreversible breakdown, an ending to an individual’s physical powers, senses and cognitive abilities. The National Counsel for Palliative Care (2012) Cancer Research UK (2014) and Longaker, (1997) explain that for some people, death is more than just physiological

process. It can also be a profound emotional or spiritual process. It appears that dying can encompass a number of different processes for the individual depending on their beliefs, culture or religion. Rittman, Paige, Rivera, Sutphin & Godown (1997) comment that nurses hold a commonly held value that puts meaningful relationships with patients at the forefront of their work in order to get to know and understand the patients' experience. From perhaps a simpler perspective, Lévinas (1994) (as cited in Lavolie, Blondeau & De Koninck, 2008) offers the idea that human suffering imposes a moral obligation of being present for the other. That the sufferer would 'call' for a presence or accompaniment. It would seem that the 'other' would be there to offer compassion to the dying in a time of profound solitude. Lavolie, Blondeau and De Koninck (2008) comment that if Lévinas' notion of a 'call' applies to all humans, then nurses in particular will be affected. Iranmanesh, Axelsson, Sävenstedt & Häggström (2010) similarly comment that nurses create close relationships with their patients, providing comfort by sharing space and time to meet their physical and spiritual needs. This time and space enables nurses to discover the wishes of the dying person. Iranmanesh, Axelsson, Sävenstedt & Häggström (2010) also comment on the important role that nurses play in building up relationships with family members and relatives.

It would seem that the demands of nursing the dying from an emotional, spiritual and physical care perspective requires in depth knowledge of the dying process, empathy, patience and dedication.

2:4 Perceptions of a Children's Hospice

“Children’s hospices provide lifelines to families at a time of unimaginable pain. The support they give is vital...Far from being a clinical, depressing place for sick children, it was a home. Most importantly, it was a family home, a happy place of stability, support and care. It was a place of fun...” (Middleton, 2014)

The concept of a CH has historically evoked fear and anxiety. There are many myths and misconceptions concerning the focus of CHs amongst the public and professionals alike (Malcolm, Forbat, Knighting & Kearney, 2008). It could be argued that this is partly due to the movement from death being perceived as a ‘natural process’ prior to the 20th century, to death now being addressed from a more professionalised medical perspective. As a result there has been movement from death in the home, to death in hospital or in a hospice. Hospitals and hospices have hidden death making contact with dying people or a dead body an unknown phenomenon. Consequently death can evoke fear and anxiety resulting in denial, avoidance and repression. It is these feelings and behaviours that have caused the notion of death and dying to become a taboo subject for many. If we look at the fear of death and then combine it with the unfairness of a child’s death, the concept of a CH becomes a highly emotive subject, which for a large majority of people is too terrifying to explore (Halliday, Boughton, 2008; Aiken, 2000; Help the Hospices, 2013). Since the mark of the modern hospice movement in 1967 by Saunders, hospices have attempted to challenge this taboo although it appears that CHs today are still questioning if and how this perception can be challenged; “Should we change the public perception that hospices are just for dying when most work is

about providing appropriate care for children to live...?” (Together for short Lives, 2013) “Is there not more mileage in changing people’s perception of the hospice as a place to die...?” (Help the Hospices 2013). Malcolm, Forbat, Knighting & Kearney, (2008) explain that in comparison to when hospices were first introduced in 1967, CHs are recognised as being much more than a place of death and dying. CHs offer a wide range of supportive services including hospice respite, home care respite, sibling support, including a number of different therapies such as counselling, hydrotherapy, play therapy, music therapy and complementary therapies. Hospice nurses and doctors can assist the child and their family in symptom management and pain control. Hospices are most widely recognised for their specialist skills in caring for those at the end of their life, and this is achieved through a holistic, person centred approach to care (Malcolm, Forbat, Knighting, Kearney, 2008; Armstrong-Dailey & Zarbock, 2001; Hill, 1994; Connor, 2009; Claire House, 2013; Derian House, 2013; Hope House, 2013). The literature I have presented in this section demonstrates a brief overview of how CHs have attempted to challenge the misconceptions that are associated with the nature of its work. It appears that the strategy for challenging these myths has been by trying to focus on the lighter or more positive aspects of what CHs services can offer to a child and their family. Although the aspect of death and dying has not been forgotten, it appears from the literature that it has been somehow hidden or masked to protect people from the truth. This seems to be a prevalent gap described as being ‘curiously silent’ not only from a hospice perspective, but from a psychological health perspective (Crossley, 2001, cited in Mercer and Feeney, 2009). For example, exactly what does end of life care look like in a CH? And what does care of the deceased child in the CH setting mean? The literature that is offered from both a non-academic and academic

perspective does not address many aspects of the phenomena I have experienced whilst working in a CH.

2:5 Nursing in a Children's Hospice – The Emotional Labour of Caring for the Dying and Deceased.

“When I am preparing the baby for the parents go through a grieving process every time. You can't help it, when you look at that small lost life.” (Staff nurse, 1994 as cited in Bolton, 2000)

At the forefront of care for the children in a CH are nurses who play vital roles in providing specialised care to children who have life limiting conditions (Feeg, Miller-Thiel, and Will, 2001). A CHNs role encompasses a wide range of responsibilities, some that are perhaps expected in any kind of nursing role, such as management of pain, helping to bath, toilet, administer medicines as well as engaging the child in fun activities where possible. But there is another side to CH nursing that many people are not aware of by many people outside of the hospice movement. From my experience I am aware of regularly occurring instances where nurses are responsible for providing information for parents to make life and death decisions, making the initial announcement that a child has passed away, for changing and dressing a child ready for his or her funeral, but yet there is very little qualitative research to reflect the impact of these experiences have on a CHN. This could be accountable to that lack of research into the lived-experience of palliative nurses working not only in hospices but in other health care settings (Rasmussen, Sandman

& Norberg, 1997; Kirshbaum & Wilson, 2011; DeArmond, 2013). Bolton (2000) released a research paper that exposed some lived-experience extracts of a hospital neonatal nurse which highlights some 'traumatic' lived experiences, taking photographs of deceased babies and creating mementoes for parents, preparing the baby for viewing, and the processes involved in 'masking' their feelings. One of the closing extracts offered highlights the 'hiddenness' notion of the darker aspects of nursing that was explored in section 2:4, "No one has any idea what we do for these women. It's a closed world and who wants to know about ugly dead babies." (Staff nurse, 1997 as cited in Bolton, 2000). This paper proves to be the only one that really begins to look at the authentic experience of a palliative children's nurse. Although there has been little research into specific lived-experiences of CHNs, it has however been documented and recognised that, "...a potential source of stress for hospice nurses involves the exposure to a rapid succession of deaths..." (Hawkins, Howard & Oyebode, 2007) and "...staff working in cancer and palliative care services are frequently exposed to the pain and suffering of patients..." (Ablett & Jones, 2007, p.733). Keene, Hutton, Hall & Rushton (2010, p.185) explain that "...in response to the death of a patient a health care professionals may experience physical, emotional cognitive, behaviour or spiritual distress..." The research seems to recognise that there is an emotional impact attached to the care of dying children despite the care setting, but there is nothing that exposes the verbatim, authentic lived-experience of a CHN in the United Kingdom.

2:6 A Hospice Nurse's Personal Mortality Exploration

“While the nature of their experiences remains unknown, there are many elements supporting the orientation of hospice workers to, intuitively and unconsciously, strive for encounters with death.” (DeArmond, 2013, p.282)

The research reveals that the majority of nurses who care for those in the palliative and end of life care stages inevitably question their own mortality (Whittle, 2002; Albett & Jones, 2007; Mckay, 1991; Payne, Dean & Kalus, 1998; Hackett & Palmer, 2010; Peters, Cant, Payne, O'Connor, McDermott, Hood, Morphet & Shimoinaba, 2013). Iranmanesh, Axelsson, Sävenstedt & Häggström, (2010, p.90) explain that for nurses, “...a variety of feelings and experiences are evoked in the face of death. The research in this area also suggests that if nurses can be open and true towards their own mortality then their communication, general being, empathy and overall nursing skills will contribute to the patient's potential to experience a 'good death' (Peters, Cant, Payne, O'Connor, McDermott, Hood, Morphet, Shimoinaba, 2013; McNamara, Waddell, Colvin, 1995; Whittle, 2002). Peters, Cant, Payne, O'Connor, McDermott, Hood, Morphet, Shimoinaba (2013) and Whittle (2002) continue to explain that providing opportunities such as death education programmes and group support networks within the workplace can assist in attributing meaning to death experiences. Creating meaning can enable nurses to become empowered to be 'open' to their own mortality which in turn may assist in developing positive attitudes to death and dying. McNamara, Waddell, Colvin (1995) offer a more evolutionary perspective posing that an 'openness' to one's mortality unfolds and matures in the form of resilience and philosophy building based on a shared commitment to a

system of hospice values. It seems that there is different fields of thought surrounding how a nurse becomes 'open' to their own mortality, however it is clear that being 'open' to one's mortality is an key factor in assisting in creating a 'good death' for the patients they care for.

There is wide recognition that nurses do question their own personal mortality as a result of caring for the dying, however the main aims of the research seem to be focused around on how this affects the patient's quality of life. This seems to be the case with the majority of research papers. I find that there are two drawbacks with such papers. The first being is that the primary focus is how this affects patient care, not how this personally affects the nurse. Secondly the vast majority of papers are quantitative in nature, presenting very few qualitative lived-experiences. Overall it seems that the process in understanding ones' mortality and the emotional labour attached to this is under researched. Sliter, Sinclair, Yuan & Mohr (2014, p.759) comment that "Despite multiple calls for research, there has been little effort to incorporate topics regarding mortality salience and death anxiety into workplace literature." The research Sliter, Sinclair, Yuan & Mohr (2014) carried out looked at how death anxiety relates to staff occupational health outcomes as well as how work experiences can impact up death anxiety and mortality salience. Although the participants in this study did include nurses, it also included other professions such as firefighters and was researched in the United States of America.

From a hospice perspective, what is available is a recent American research paper that focuses on the psychological experience of hospice workers. This paper does utilise verbatim lived-experiences and communicates to the reader how hospice work changed their interpersonal relationships and how their personality changed through hospice work. They explained a feeling of less fear of death, more

compassion and peace resulting in changes in lifestyle outlooks, stronger relationships and an increased appreciation of life (DeArmond, 2013). This paper sits alone in its attempt to unearth authentic lived-experiences of those working in hospices and the existential impact this has on these individuals. This research paper represents the closest parallels to my research focus, but is not specific to CHs, the nursing role and was not based in the United Kingdom.

2:8 Summary

What has appeared as a result of this literature review is that a CHN's role is ill-defined, perhaps arguably hidden or masked. A brief look into the historical perspectives of death and dying prior to the development of the hospice movement, and the notion of 'unfairness' surrounding the death of a child provides a possible explanation as to why the CH movement is still feared and unknown to many people. Could this state of fear be so imbedded within society that academics and hospices themselves are fearful of researching and presenting the authentic side of CH nursing? The research that has been conducted verifies that CH nursing is emotionally demanding and that hospice nurses do question their own mortality. Without adequate and appropriate research into the authentic lived experience of a nurse working in a CH, how can hospices be sure they are providing the correct and adequate support required to assist nurses on their personal mortality journey?

I hope that through interviewing relevant participants these authentic and lived experiences may be revealed along with accompanying feelings and emotions surrounding personal mortality. Through this I hope to consider the role counselling could play in supporting staff in exploring their mortality.

CHAPTER 3: METHODOLOGY

3.1 Philosophical Perspective and Design

There were two main research enquiry options I considered for this study; these being quantitative research or qualitative research.

Quantitative research is the most traditional and dominant form of research and takes on a positivist paradigm. This method works to reduce all of the unique aspects of the environment, in order to apply the results to the majority, creating an assumption of a single reality (Maykut & Morehouse, 1994; Sanders & Wilkins, 2010). In order to create single realities or defined categories, 'subjects' are quantified through a process of standardised scientific experimenting, measuring and recording, creating a reliable set of statistics. (Denscombe, 2003; McLeod, 1999; McLeod, 2003). In contrast to this rigid 'single reality' approach to research, there is a newer multiple reality concept. This is known as a qualitative approach which "...values context sensitivity, that is, understanding phenomena in all its complexity and with a particular situation and environment." (Maykut and Morehouse, 1994, p.23). Within this process an inductive, holistic and reflective approach is taken to elucidate meaning and discover a number of realities from the data.

Willig (2001) explains that choosing a method appropriate to the research question is paramount. The primary aims are to identify specific experiences within the hospice that trigger personal mortality exploration and to explore the depth of personal thoughts and feelings surrounding one's own mortality in relation to these experiences. This can be achieved through gaining an understanding of these depths through language that elicits rich data of an individuals' experience and

meaning of the phenomena (Polkinghorne, 2005; Patton, 1990). In addition to this, qualitative research in my chosen area of study is limited; therefore it makes sense that my research should be qualitative in nature. With foundations in a phenomenological philosophy, from a wider perspective, qualitative research also falls neatly into the field of person centred counselling. Carl Rogers, founder of the person centred approach in counselling states “Every individual exists in a continually changing world of experience of which he is the centre” (Rogers, 1951, p.483). It is this unique, lived, personal experience and reality I wish to curiously explore through my research question and hence another rationale for my choice to use a qualitative research method for my study.

In employing qualitative research methods there is one potential limitation I feel is worthy of exploring at this point. According to Moustakas, (1994) and McLeod, (2003) it is the role of the researcher to become absorbed in the data in order for deep and meaningful analysis to take place, but yet the researcher should be able to separate him/herself from the material as to not influence the data in a bias or judgemental fashion. Elliott and Williams (2001) describe this expectation as a ‘paradox’. It is this paradox that I feel could potentially limit the validity of my research as I feel intently aware of my position within this research process due to my hospice work background. Taking into consideration that I wish to create a safe space for each participant to truly recount their experiences I feel it is important to use Husserl’s process of ‘epoche’ which Wertz, (2005) describes as “.... abstentions from influences that could short-circuit or bias description.” This will require me to set aside or bracket off assumptions gained through personal experiences when collecting and analysing the data in order to get “to the things themselves” (Husserl, 1962, p.385). In contrast, West and Talib (2002) argue that prior experience is not a

limitation but is beneficial to the research. My interpretation could offer another way of looking at the findings or could support the findings to create a better overall understanding.

Taking both views into account, respecting the validity and also the limitations in practice of each of them creates a hard balancing act for a novice researcher such as myself.

3.2 Sampling

“Sampling, must be theoretically consistent with the qualitative paradigm in general ...” (Smith, Flowers and Larkin 2009, p.48). As discussed previously, the purpose of qualitative research is to gain a deep and rich understanding of an individuals’ experience and meaning of the phenomena (Polkinghorne, 2005; Patton, 1990). Therefore advertising and selecting participants who can provide detailed insights into my research area is imperative to this small, time bound study (Denscombe, 2003). For this reason I will use purposive sampling, with the aim of obtaining four to six participants to meet these requirements.

I sent out advertisement packs which consisted of a covering letter and research advert in both hard and soft copy formats (Appendix 2 and 3) to twelve CHs. Of these twelve, six responded and agreed to advertise my research in their staff rooms. Out of these six CHs, only one participant was generated. I was disappointed with this outcome and had to think of an alternative way to recruit for participants. With time elapsing I discussed with my supervisor the possibility of advertising for participants through the CH I work for. Hewitt-Taylor (2002, p.33) explains “...the time required and the cost of the research might make it impossible

for practitioners to carry out in depth qualitative research in other organisations, instead they may decide to carry out insider research.” I recognised at this point that if I am interviewing colleagues there may be an impact upon the validity and trustworthiness of my data. I will explore this potential in more detail further on in this chapter.

When advertising for participants in my work place, I ensured that throughout the process I remained mindful of the ‘opting in ethos’ (Bond, 2004). Although it would have been easy, I did not directly peruse potential colleagues. All participants approached me and voluntarily offered their time and expertise. This advertising process proved to be very successful and I was able to recruit another three participants. In total I managed to recruit four participants for this study, three from my place of work and another from a different CH all of whom met the inclusion criteria (Appendix 5). It is also worthy of noting that all participants in this study are female.

3.3 Data Collection

Once the participants had made contact with me registering their interest, I sent out a ‘participant information sheet’, detailing the questions to be asked in the interview (Appendix 5) and a ‘participant questionnaire’ (Appendix 6) to ensure they met the inclusion criteria. Upon meeting the criteria I used email, phone and face to face communication to arrange a date and time for interview and to send out the first consent form (Appendix 8). I ensured I booked appropriately quiet and confidential rooms in good time and contacted participants a few days before to ensure their participation.

Before the interview started I welcomed the participant and reiterated the aim of the interview, allowed time for questions and ensured the second consent form was signed (Appendix 9). The interview then began. My data collection strategy utilised a recorded semi-structured interview process as research showed that this would be the best way to accurately capture the participants lived experiences (Sanders & Wilkins, 2010; Polkinghorne; 2005, Wertz, 2005). This form of interview took on a loose structure consisting of eight opened questions and prompts (Appendix 10). The questions were designed in such a way that they initiate interaction surrounding the area to be explore, but also allow time and space for the participant and interviewer to meaningfully diverge in order to explore an idea in greater detail. It was hoped that by using this interview structure the questions will elicit relevant and rich responses (Britten, 1995; Thomas & Hersen, 2003; Mintz 2010). The challenge I faced was one that Willig (2001) talks of the necessity of acquiring relevant information whilst also being respectful and letting the participant go where they feel is relevant. I feel I overcame this throughout the process of interviewing as I became increasingly confident in my ability to ask on the spot prompting or probing questions. The balance was ensuring that what I asked was not to influence but to facilitate (Eatough and Smith, 2008). According to Kvale (1996, p.105) "The outcome of the interview depends upon the knowledge, sensitivity, and empathy of the interviewer." Therefore throughout the process of question planning and when delivering the questions in the interviews, it was important to remain mindful of the sensitive nature of the topic of enquiry, employing sensitivity and empathy as suggested by Kvale (1996) and Bond (2004) .

The interviews lasted between thirty-five minutes and an hour. All interviews were recorded through a dictophone. After the interviews I had a short debrief with

the participant and explained the process of transcript checking, anonymity and withdrawal before thanking and saying goodbye to participants. Post interview the interviews were transcribed verbatim which and become my research data. The transcript was sent to the participant to check for errors or omission before data analysis took place.

3.4 Data Analysis

My chosen method of data analysis is Interpretive Phenomenological Analysis [IPA]. My rationale for using this method is that one of its main roots are based within the field of phenomenological enquiry. (Brocki & Wearden; 2005, Biggerstaff & Thomson; 2008.) The IPA method supports that individuals are not passive perceivers of phenomenon, but are active perceivers. Individuals work to interpret phenomenon to gain understanding through creating realities that make sense to them. This view falls in line with the person centred approach to counselling, forming a firm theoretical grounding to my data analysis which is in keeping with the philosophical underpinning of this research.

As IPA also has roots with the theory of hermeneutics, there has been some criticism surrounding the method. Other qualitative data analysis methods allow for the emergence of themes to take place but are then only presented through a descriptive account. This can only be considered to 'bear witness' to the experience (Barbour, 2007). By going beyond this practice and creating a second stage of data analysis, as IPA offers, allows for rigorous analysis or interpretation of the data. This allows for exploration of these experiences helping researchers to make sense of their participants experience. The risk concerned with this second stage is that the

participant's voice may get lost through rigorous researcher interpretation and therefore the research could lose some of its validity (Willig, 2008; Pringle, Drummond J, McLafferty and Hendry, 2011). Denzin, (as cited in West and Talib, 2002) comments that all research is about the researcher, although in order for the research to be of value the researcher must ensure that the research moves beyond him or herself. As a novice researcher I feel that being sensitive to this potential and reminding myself of my process within the research is important if I am to 'go beyond' myself. In order to regulate this I intend to keep a personal journal of my thoughts and feelings, use my supervisor as a form of triangulation and maintain an accurate audit trail. According to Reid, Flowers and Larkin; 2005 and Biggerstaff & Thompson; 2008 these are effective methods of remaining grounded within the research process and also provides evidence for validity.

The process I underwent involved detailed engagement with each transcript one at a time. This was achieved through transcribing, reading and rereading, immersing myself with the data and reflecting on my thoughts and feels that evolved. I ensured I kept an accurate and thorough record of this process, evidence of this can be seen in appendix 11. Following this I began to make descriptive comments that highlighted any linguistic features such as laughter, tone of voice and fluency (Smith & Flowers, 2009). The second stage of the analysis process gave me an opportunity to explore conceptual elements this enabled me to explore personal reflections. Smith & Flowers, (2009) highlights that it is important to recognise that this stage is to enable the researcher to open up a range of possible meanings, not to offer answers or explanations.

The next stage involved creating a list of emergent themes for each question. I achieved this by cutting out key extracts of the data that link closely to the question

I was asking. The next process was to identifying common elements throughout the text for the question in order to create a bank of super-ordinate themes (Appendix 12). This then led me to the last stage of the process where I could look across all the data and questions looking for patterns, comparing themes to discover close linking or opposite findings. This then created my table of master themes (Appendix 13).

3.5 Validity and Trustworthiness

The modification I had to make in the early stages of advertising meant that my sample had to change from participants I did not know to participants who were colleagues. This modification meant that I needed to become aware of the impact interviewing colleagues could have upon the validity and trustworthiness of the data I received and the findings. Edwards, 2002; Brannick & Coghlan, (2007) talk of the term 'insider research' explaining that this kind of research is undertaken by a person who is a member of the organisation or group that are being researched. According to Edwards, (2002) Hewitt-Taylor, (2002) and Coastley, Elliott & Gibbs (2010) the privileged nature of this kind of research is unique. All comment that deeply imbedded organisational knowledge, history and personal relationships possessed by the researcher are undiscoverable to outsiders. It is this prolonged engagement, specialist knowledge that enables the researcher to study a particular issue in depth. This perspective serves to aid research validity. In contrast, Morse, (1998, as cited in Denzin & Lincoln, p.61) definitively states "It is not wise for an investigator to conduct a qualitative study in a setting where he or she is already employed and has a work role." Brannick & Colghan (2007, p.59) comment "The

dual roles of investigator and employee are incompatible, and they may place the researcher in an untenable position.” It is not that the positivist insider researchers reject Morse’s argument, in fact they also comment upon the possible shortcomings of insider research. Edwards, (2002) Hewitt-Taylor, (2002) Brannick & Coghlan, (2007) and Coastley, Elliott & Gibbs, (2010) all comment that because the researcher is so familiar with the organisation and the people within it, that indeed in some cases the data collection process does not create the distance and objectivity required. The researcher may become bias or complacent to nuances and subtleties. This creates the argument that insider research loses its trustworthiness and validity. The difference is that unlike Morse (1998) the majority of researchers believe that these potential issues surrounding trustworthiness and validity can be minimised by employing a number of strategies. Zavella (1996) comments on the ‘simultaneously insider – outsider status’ of insider researchers and it is balancing these two positions that faces me in my challenge to elicit valid data and trustworthy findings in my research. Glesne (1989) and Edwards (2002) explain that rapport and trust should not be assumed and nor should it be taken for granted given the role change. Edwards (2002) and Hewitt- Taylor (2002) comment that the researcher needs to be self-aware, exploring the issues of connectedness with the organisation and how this can influence the results and interpretation of them. Brannick & Coghlan (2007) believe this can be achieved through reflexivity and will assist to ensure that objectivity of findings and not the researcher is achieved. From a practical perspective Hewitt-Taylor (2002) suggests ensuring that interviewees describe and discuss events from their perspective to avoid later researcher interpretation. Coastley, Elliott & Gibbs, (2010) highlight the importance of feedback from

participants, triangulation methods and an awareness of the issues represented in the project.

I feel the research I have undertaken in insider research has enabled me to begin to consider the impact of a dual relationship with my colleagues. It has highlighted the importance of self-awareness and the need for effective epoche and reflexivity. Also, by holding a debrief after the interviews as well as having an outside supervisor I feel that I will be able to gather data and interpret findings that are both trustworthy and valid.

3.6 Ethical Considerations

Bond (2004) states that “One of the widely agreed characteristics of high quality research is that it should be ethical.” Throughout this research process I am representing Chester University and the British Association for Counselling and Psychotherapy [BACP]. Therefore it is my responsibility to be aware of potential ethical pitfalls in my research to ensure the wellbeing of my participants.

Participant anonymity was maintained throughout the process by creating a pseudonym. Any correspondence with the participant took place in a confidential space or via secure email. All personal information and interview data collected from the participants was securely stored. Confidentiality was maintained throughout the process where applicable. Participants were made aware of these procedures and confidentiality limitations through participants information sheets and were asked to sign a process consent form prior to conducting the interviews. Bond (2004) explains that clients will have the right to withdraw from the research including data collection

and analysis stages. Therefore at the point of writing up the findings and dissemination of the research, participants could not withdraw.

Due to the sensitive nature of the research question I was aware that the questions may evoke painful memories or give rise to new unexplored vulnerabilities for participants (Bond, 2004; BACP 2007; McLeod, 2003). To a degree my exclusion criteria guarded against this risk as it clearly excludes those who may be currently vulnerable due to personal bereavement or illness. Even with these exclusion criteria in place, it cannot be assumed that participants will not be adversely affected. Therefore I ensured that participants had my contact details should they need to be put in touch with a list of counselling agencies that can offer additional support post interview if required.

Before any of the research started I had to gain ethical approval from the University of Chester who highlighted pitfalls that need addressing before this research could be carried out. I have been regular contact with my university supervisor who has assisted me in monitoring my ethical obligations throughout the process. The research conducted was guided by the principles of the BACP Ethical Framework (2013). Ethical considerations were treated as paramount importance throughout the whole of this research.

CHAPTER 4: FINDINGS

4:1 Introduction

This chapter will thematically present the findings following analysis. I will present five master themes divided into eighteen sub-ordinate themes. (See Fig.1). Smith, Flowers & Larkin (2009) explain that for trustworthiness of the identified master themes, it is necessary to include extracts from each participant. For quality purposes I have ensured this is the case. Evidence of data from each participant for each master theme is also demonstrated in Appendix 13 and 14. Verbatim quotes will be used throughout the findings to reveal participant phenomena and give voice to the research as well as providing evidence to support my analysis and interpretations. This sits in keeping with phenomenological, qualitative grounding of the research. The four female participants in this study have been given pseudonyms to ensure the participants confidentiality. Throughout the extracts, it will be noticed that three dots (...) will appear. These dots highlight areas of data that have been purposely omitted, as it was felt that the data was irrelevant to conveying the relevant meaning. For participants profiles please see Appendix 7.

Master theme number	Master theme name	Sub-ordinate themes
1	Phenomena	<ul style="list-style-type: none"> • Covert phenomena • Hospice culture and societies perception • Care of the child • Experiences external to hospice
2	Emotional and behavioural impact	<ul style="list-style-type: none"> • Emotional impact • Behavioural impact • Increased awareness of own mortality • Increased professional awareness
3	Mortality salience	<ul style="list-style-type: none"> • Value/meaning of life • After death
4	My child's mortality	<ul style="list-style-type: none"> • My mortality vs my child's mortality • Similarities and comparisons
5	Coping mechanisms	<ul style="list-style-type: none"> • Hospice support • Family • Recreational time • Self-awareness and boundaries • Remuneration

Fig.1 Table of master themes identified by cross sample

4:2 Phenomena

4.2.1 Covert phenomena

Two nurses describe how working in a CH exposes them inside knowledge and information that they would not likely to be exposed to if it was not for their role.

“You get privy to a lot of knowledge when you work here...” (57-58, Yasmin)

"...a lot of other people that didn't work in this setting I suppose they think when you die you die, em whereas we know a little bit different...you see behind the scenes" (58-61, Pippa)

4.2.2 Hospice culture

Nurses Pippa and Yasmin describe aspects of their experiences of the CH culture and how this differs from a hospital care setting.

"...not that hospitals don't care but that's not their specialism that's not what they are geared up for, they don't have the time, they don't have the resources, whereas a hospice, that's their niche" (110-112, Pippa)

"...when I worked in a hospital when a child died it was very much you took them from the ward and you took them to the mortuary and that was pretty much your involvement you had, whereas here it is very different your very hands on..." (145-148, Yasmin)

*"...our children here are never by themselves when they die, the family is all around them...if they want to go to Chester Zoo we try and do that for them and make memories...even the ***** just to think you could be in a place like that and not be in a fridge mortuary." (123-126, Gwen)*

Pippa and Yasmin continue to describe exactly what makes the culture of care in a CH so unique.

"Time, giving families time, we have one-once care...giving families private space, the children have their own bedroom, the sitting room...visitors come...you've got the garden... people who understand the difficult time you are going through to have empathy, to be there to support you and to listen to you, to make sure you get your wishes, the things that are important to you, the memory making..." (115-123, Pippa)

"We support them with em all the paperwork, order of services, things that they might not of had any experience of doing..." (130-131, Pippa).

Beth and Pippa comment on society's perception of a CH and the taboo elements of death and dying that are both integral and fundamental aspects of their role as a CHN.

“...when you say you work in a children’s hospice people go oooohhh really and they think its really sad and its not. It’s a really happy and wonderful place...and it is sad that in our society today death and dying is not talked about because it’s the one thing that is guaranteed, you will die one day...people feel so uncomfortable talking about it.” (75-80, Pippa)

“I don’t talk much about that with my husband...my husband says oh switch the plug, turn the plug off that sort of conversation...” (151-152, Beth)

4.2.3 Care of a child

When the participants were asked to comment on phenomena within the hospice which led them to think about their own mortality all the nurses commented upon their experiences in cold rooms.

“...we have to wash and dress them, we care for them daily em it might be changing their pad, changing their clothes... em doing handprints, doing all the mementoes and things like that...” (62-65, Gwen)

*“I’ve washed someone’s hair in the ***** which was quite traumatic, her hair was falling out...” (65-66, Gwen)*

“...we shouldn’t have to see some of the things we see with dead children, how they look and blisters and things like that...” (68-69, Gwen)

“...she continually leaked... the nurses went up in twos to change the sheets underneath her...(248-252, Beth)

There was one occasion where a little boy had been in there when it was quite warm ...he had been in there for over two weeks before his funeral...it was not nice at all...a lot of deterioration em hands and feet were black...” (44-49, Yasmin)

4.2.4 Experiences external to hospice

Three nurses talked of death and dying experiences external to the hospice.

“...I was about nine and my family are from an Estonian background and it is tradition that you say goodbye to the body, you have an open casket, you go and visit, you kiss.” (P, 63 -65, Pippa)

“...I was always very comfortable around dead people...I was used to death and dying being around, I could see the importance of getting it right and how

it made you feel...and that someone was still important even though they had passed away..." (P,66-69, Pippa)

"...both my nans were in immense pain...one of them was by themselves...someone had found her in the morning...she died by herself in pain..." (120-123, Gwen)

"...I think I was doing an assignment on end of life care, and I was looking after a girl, who was dying in the hospice, my sister had a baby girl at the time and that because I had a still born baby over twenty years ago brought that all back to me...and that was really difficult." (25-30, Beth)

4:3 Emotional and Behavioural Impact

4.3.1 Emotional impact

Gwen shares a detailed insight into her feelings of being a CHN.

"Upset, really really upset that it can happen and angry as well for this poor little boy what's happening to him." (37-38, Gwen)

"...when he was first diagnosed with his condition... it made me cry..." (18-19, Gwen)

"I'm a senior nurse and I felt awful...I'd sit in handover thinking please don't give me that child..." (19-20, Gwen)

"...you're meant to be the one that can do anything because you're the senior person" (26, 27,21,22, Gwen)

"...I felt guilty that I felt like that because he's another child that should be able to care for, but I couldn't...I should be able to do my job." (40-42, Gwen)

*"...you do feel guilty because sometimes now I don't think twice about going into the ***** (89-92, Gwen)*

"...who else has to do things like that in their job..." (85-86, Gwen)

"You feel like you could be an undertaker sometimes because of what you have to do." (108, Gwen)

Yasmin and Gwen comment on the emotional impact of experiences they recall as being traumatic.

“...it was one of the worst we have had to deal with...I think we both felt a little bit traumatised...that was possibly the worst...it was not nice at all...” (44-50, Yasmin)

*“I’ve washed someone’s hair in the ***** which was quite traumatic, her hair was falling out...” (65-66, Gwen)*

Yasmin further comments on the permanency of these memories and the emotions attached to it.

“I think I will always reflect back on it...I don’t think that will ever go away...” (74-75, Yasmin)

Beth also speaks of difficult memories.

“...your remembering all the families that you have cared for who have lost a child...that’s really quite hard...” (79-80, Beth)

4.3.2 Behavioural impact

The nurses talk of behaviours they have been aware of adopting when working in a CH.

Gwen describes her behavioural response to this situation:

“...when he was first diagnosed with his condition I couldn’t look after him...I couldn’t go near him...” (18-19, Gwen)

“... I couldn’t go in and do medicines or I’d go in and I would have to face the other way, I couldn’t look at him at all...” (25-26, Gwen)

Yasmin and Gwen talk of a behaviour whereby they talk to the deceased child in the cold rooms when carrying out personal cares.

“...still treating them like they were alive, talking to them...” (67, Gwen)

“...I always just try and think they are just asleep and you just talk to them like you normally would.” (39, Yasmin)

Gwen also recognises she has adopted a passive behaviour when going to the cold room.

*“...I don't think twice about going into the ***** I just do it and it doesn't affect me at all but later on you think why doesn't this affect me anymore... have I been doing it for too long?” (89-92, Gwen)*

Pippa behaves by planning and tell others of her wishes.

“... you never know when you're going to die or need palliative care...it's good to plan beforehand...” (211-212, Pippa)

“...I tell him about organ donation, I want this going, I don't care what they take, they can have anything they want.” (170-171, Pippa)

4.3.3 Increased awareness of own mortality

All four of the nurses comment on how the experience of being a hospice nurse has increased their awareness of their own mortality.

“...if I had a serious illness and I was palliative I would like to think that I might be able to stay at home...I wouldn't mind if I had to go into a hospice but I'd rather obviously be at home...” (66-102, Pippa)

“It definitely make you think about the end and how you, what would be important to you.” (20, Yasmin)

“For me I see palliative care and death and dying as a positive thing not a negative thing and that it is important to think about what is important to you, what your thoughts and feelings are about death and dying...” (209-211, Pippa)

“...I want to be cremated, I don't want a burial site, I want my ashes to be thrown over Moel Famau ...I hate church yards with all the gravestones I think they are a waste of space...you could use up that space for a park for kids to play in...” (91-95, Pippa)

“..it is surreal that you could organise a funeral yourself, cos you know what your doing...” (108,111, Gwen)

“...I constantly think of about what hymns I'm going to have and who's going to say what...” (102-103, Gwen)

“I'm quite clear about what I would or wouldn't want at the end of my own life...” (168-169, Beth)

4.3.4 Increased professional awareness

For two nurses emotional impact is reflected through their professional awareness.

“It makes you think how you would do things differently...how you can do your job better...” (76-77, Yasmin)

“I was doing all three together...that occasion really brought home to me how difficult our job is sometimes and how much we take on as nurses em over and over again.” (35-36, Beth)

4:4 Mortality Salience

4.4.1 Value/meaning of life

Three of the nurses commented that their role as a hospice nurse has made them consider the value or meaning of life.

“It makes you think how precious life is ...” (17-18, Yasmin)

“...it shows how fragile the human body is...and how once your gone your gone, that there's not much left, so yeah I suppose it does spark, strike a

chord with your own mortality, that's what happens its very factual..." (55-57, Yasmin)

"I think every family that you care for makes you think about life and what's life about, what are we here for, what's the purpose, what's the bigger picture, is there anything after you've gone..." (17-19, Pippa)

Nurses Yasmin, Gwen and Pippa offer an appreciation that they are not infallible or exempt from death.

"...it just reinforces the fact that life is very short and you don't know what's around the corner." (27-28, Yasmin)

"...and what's to say that it won't happen to me..." (31, Gwen)

"...it's the one thing that is guaranteed, you will die one day." (75-76, Pippa)

4.4.2 After death

The nurses primary concern surrounding the events after death was a concern of how others, mainly family, would feel and cope without them.

"...how many people will be crying" (103-104, Gwen)

"...how are other people going to feel after I've gone..." (3-4, Pippa)

"I'm thinking how it might affect you know people em around me..." (6, Beth)

"I think about it more that way, how it impacts on others..." (9, Beth)

Pippa comments on the thought of her own death and the potential pain this would cause her loved one.

"...how other people would cope, of course they would cope but you know the feeling that they would be in pain and upset makes me upset." (57-58, Pippa)

To Pippa, the potential reality of her death brings about feelings of sadness in the thought of missing out on being a part of children's significant milestones.

"...not being able to see the kids go through their stages in their life special things happening getting married those kinds of things..." (8-10, Pippa)

"The bits I wouldn't be a part of." (12, Pippa)

4:5 My Child's Mortality

4.5.1 My mortality vs my child's mortality

When the children's' hospice nurses were questioned about their own mortality, two of those nurses who had children comment that they think of their child's mortality more than they do their own.

"I don't think its em seeing children die em doesn't em really bring my own mortality to mind em ...really more so of my children." (66, Beth)

"It's not so much myself, it's my children because my children are the most important people in my life so how would I feel if anyone of them needed end of life care cos I wouldn't want them to suffer, so having those ideas in my head really. What would be acceptable, what would not be acceptable, yeah definitely" (247-250, Pippa)

Yasmin, the youngest nurse in the study, and the only nurse who does not have any children comments,

"I haven't got any children so mean...if you were a mum, because I'm not a mum, I'm not, I would never know how they, you can only ever empathise with people." (112-114, Yasmin)

"...I do definitely think when I, if I ever do have children, working in this job I think I will find it a lot more difficult than I do at the moment..." (116-119, Yasmin)

4.5.2 Similarities and comparisons

All of the nurses commented that they had experiences of children and families with whom they can identify with on a personal level.

"I think the hardest part things is when you have a child or a family come in who you can slightly identify similar things to your own because you can't help but make that comparison sometimes." (45-48, Pippa)

"...the children that have had cancer or brain tumours or the ones that have been normal like your own children...you put yourself in their positions..." (10-11, Gwen)

"...there will always be similarities and you'll always be able to connect something somewhere." (101-102, Yasmin)

"I think working in a children's hospice sometimes the link is if you're looking after a child who's died who possibly you have someone of a similar age in your family...their mortality comes to mind." (12-16, Beth)

Gwen comments on an experience when she saw similarities between a child she cared for in the hospice and her own son. (Please see corresponding extracts in Master theme 2.)

"The child is exactly the same age as my son, was into everything that my son was into, looked like him, wears the same clothes as him." (17 -18, Gwen)

"...he was exactly the same age, everything about him, what his mum said about his life was just my son...it just really bothered me....I've never had a block like it before." (32-34 42, Gwen)

"...its only as he's changed with his condition and he doesn't look like my son anymore, hes well into his condition now in that he's not normal at all that I feel able to look after him..." (22-24, Gwen)

4:6 Coping Mechanisms

4.6.1 Hospice Support

Three of the nurses talk of the importance of being with colleagues or team who can provide them with emotional support.

*“We have a very strong team...I think that is our main source of support”
(B,41, Beth)*

“If I didn’t have such a big team and weren’t so supportive of each other, then maybe, I would definitely maybe looking for something else for another supportive mechanism or some form of counselling or something like that definitely something to try to help you cope.” (245-247, Yasmin)

*“I have got really good colleagues here as well who I would talk to as well”
(290-291, Gwen)*

The participants explored other areas of more formal hospice support including debriefs and one to ones.

“Usually when we have a debrief it’s about that particular child and family and we talk about what went well, what didn’t go so well, what you would do differently, how people were thinking and feeling at the time...” (157,159, Pippa)

“...debriefs at work tend to be what went well and that’s it really...” (277, Beth)

“...I think it’s a place [debriefs] to discuss the death and the care around that...the ones I’ve been to its all been about the child...I suppose there’s some feelings but not really about your feelings, more about feelings for the family.” (156-162, Gwen)

“I have one to ones with my manager and I don’t think it is something that I would really talk to my manager about... (167-168, Pippa)

“....they say 1:1 support is there but nothing formal in the form of supervision...” (272-279, Beth)

Three of the participants felt that a counselling service would be beneficial.

“I think it would be really, really useful for staff to look at their own feelings about how they cope with death of the children...some deaths effect you more than others...I think it would be really useful...” (290-294, Beth)

“I definitely think it would be beneficial, I think a lot of people would benefit from it...” (191, Yasmin)

“...it’s good talking to your friends and family but they have their own thoughts, feelings and opinions ...so to have someone in a counselling role to talk to would be fab...” (204-206, Pippa)

From past experience of counsellors, Gwen and Beth felt that a counselling service could have a negative impact upon staff.

“I think some staff would worry that it would open a can of worms...” (173, Gwen)

“...we have tried it before in groups but it didn’t really work then...a counsellor used to come in...you could have one to one sessions...I didn’t get much out of it...she was very counselley and nodded...” (177-289, Gwen)

it was really traumatic...they had never been asked that question, they had never been to consider haw they coped with it...people found it really upsetting...we had done it differently it was quite simply because I think because it was a counsellor asking how we were...as opposed to how well we had done...” (230-237, Beth)

4.6.2 Family

Two of the four nurses commented on the importance of a supportive husband.

“My husband and children know what I do...they allow me to have quiet time or to talk about things...” (141-142, Pippa)

“I have a very supportive husband...he is probably the main source of support.” (189-191, Gwen)

Gwen’s husband finds it harder to support her.

"I don't talk much about that with my husband...my husband says oh switch the plug, turn the plug off that sort of conversation..." (151-152, Beth)

4.6.3 Recreational time

Beth, Yasmin and Pippa talk of the importance of recreation time and having hobbies.

"...you do need stuff outside of work it's very difficult sometimes to switch off and I think that is an acquired art." (197-198, Beth)

"...I think having those little breaks definitely do help especially if you had a really heavy involvement..." (91-92, Yasmin)

"I like gardening, I like walking my dog..." (141-142, Pippa)

4.6.4 Personal coping strategies

There is an underlying sense that all of the nurses experience sadness and grief following the death of a child, Gwen was the only nurse to outwardly admit this from a personal loss perspective.

"...there are obviously occasions when you do lose a child here...it does feel like a little bit of a personal loss." (136-138, Gwen)

There were a number of different ways that the nurses said they cope with the emotional labour of their roles.

"...you can always rationalise things, I suppose that's how I cope." (157-158, Yasmin)

"I have to protect myself now it's not my loss, you know it's not my family, I didn't love that child...I'm older and wiser now..." (149-150, Gwen)

"...you've got to have these boundaries haven't you to be able to look after yourself... you need self-preservation as much as anything else." (75, 93-94 Beth)

Three of the nurses speak metaphorically about their coping strategies.

"...you put a hat on..." (69, Beth)

"I think it is definitely self-preservation...it is beneficial to be able to put it away." (207, 210, Yasmin)

"...I am able to switch off I used to go home and get upset and I don't seem to do that as much anymore, I think you switch yourself off..." (133-134, Gwen)

Some of the nurses use denial and detachment techniques.

"You detach yourself a little bit and just pretend that they are still alive...when you are doing things you just chat to them like you usually do, it doesn't seem real really...it's just when you come out you think, oh god have I really done that..." (79-83, Gwen)

"... you have got to look after yourself, you have got to move on because inevitably there will be another family coming your way who need your care." (82, Beth)

4.6.5 Remuneration

Three nurses all commented that they continue in their roles as CHNs as the satisfaction they gain from assisting families is highly rewarding.

"...knowing that I am doing a good job and having the job satisfaction that I have been able to support someone well and that they feel it has been a good experience." (138-139, Pippa)

"...the care that they give you know that makes me very proud to work with them..." (252-253, Gwen)

"...I love being able to care for families..." (258, Yasmin)

4:7 Summary of Findings

This chapter has revealed the master themes and sub-ordinate themes from the data, and is accompanied with verbatim quotes to demonstrate these themes. I feel that the themes I have derived through the analysis process sits in keeping with the dissertation question, and were areas that I expected would be covered by the participants. However, there was one theme, 'My child's mortality' which proved to have greater weighing to the participants than I had anticipated. In Chapter five I will be discussing these themes. I will explore them in relation to my dissertation question as well as in light of my literature review and where appropriate draw in any further relevant literature I have researched following the data analysis process.

CHAPTER 5: DISCUSSION

5.1 Discussion of Findings

The aim of this research study was to explore the impact working as a nurse in a CH has upon one's thoughts and feelings surrounding personal mortality. In this chapter I will discuss the findings relating directly to this question and the aims of the research. I will achieve this by using the master themes and sub-ordinate themes holistically to create an integrated perspective. Finally this chapter will end with some recommendations.

All four of the nurses directly comment on issues that demonstrate an awareness of their own mortality. Yasmin (27-28) Pippa (75-76) and Gwen (31) all spoke frankly about death openly expressing an awareness that their life will at some point end. Yasmin (17-18, 55-57) and Pippa (17-19) talk of the fragility and preciousness of life, touching on existential issues they have often pondered over. Beth (168-169) states that she is very clear about what she would or would not like in regard to her care at end of life, however Beth did not explain these wishes in detail. I wonder if this was due to the interview environment, fear of the subject, or because the nature of the content is too personal to share with an interviewer? Yasmin (15-16, 20) explains that working in a CH does make her think about how she wishes to be cared for at end of life, but there is still a sense of exploration and uncertainty in Yasmin's wishes. Pippa (66-102, 91-95) however, explains in much greater depth her wishes for home care and funeral wishes and explains her preferences for these choices. Knowledge of these preferences made communication possible with loved ones. When participants were directly asked about their thoughts and feelings

surrounding their own mortality the majority of nurses offered an articulate sense of acceptance of their own death and appreciation of life. Most of the nurses seemed clear on aspects of their care and funeral wishes.

The participants also offered insights into other socio-cultural and personal experiences which do seem to also have an impact upon their thoughts and feelings around death and dying. Pippa (63-65) commented on the impact of her Estonian background and the cultural traditions of death she grew up being exposed to and Gwen (120-123) talks of her experience of watching her Nans die for example. Therefore, it must not be forgotten that although my discussions are focused around the role of a nurse in a CH, these nurses have had a life time of exposure to death and dying in many different forms, separate to their hospice work and all of these experiences will be contributing to the individual's own sense of their mortality. This falls in line with Rogers' humanistic view, that each individual has a 'phenomenological field' which embraces all that is experienced by the individual both consciously and unconsciously (Rogers, 1951). It would seem that CHN adds to one's experience of death or dying and thoughts surrounding personal mortality.

The data also demonstrates that CHN's are exposed to highly unique situations which bring about the arousal of insider knowledge. These authentic experiences reveal themselves explicitly in the interview, whilst also being described and sensed as deeply intimate and hidden from those external to the hospice. Yasmin (57-58) talks of the knowledge she is "privy" to as a result of being a CH nurse and similarly Pippa (58-61) talk about how her and other nurses "see behind the scenes". Two nurses talked frankly of witnessing the body's deterioration, *'it was not nice at all...hands and feet were black'* (Yasmin, 44-49). *"We shouldn't have to see some of the things we see with dead children, how they look and blisters and things like*

that...her hair was falling out" (Gwen, 62-69). Kristeva (1982) comments on how the dead creates a portrayal of the abject. The abject is real and represents an unbreakable interconnection between life and death. Kristeva continues to explain that the proximity of the observer and the body highlights the fragility of the living. The potential power of the dead is the ability to violate physical boundaries. Perhaps the words that were spoken by these participants demonstrate an example of this power? A sense of the realisation of a stark contrast between the physicality of life and death prevails and holds disgust for the nurses.

Both Gwen and Yasmin reflect back on two different experiences and describe them both as being *'traumatic'*, this word being the same word described by Bolton (2000) in relation to his experiences of working with nurses in similar situations. Yasmin (83-86) comments that these memories end up being *'something that sticks in your mind'* and follows this up with *'I don't think that will ever go away'*. In the literature review Hawkins, Howard & Oyebode, (2007) talked of the rapid succession of deaths and how this offered a potential source of stress to nurses. Likewise, Beth (35-36) refers to being exposed to distressing experiences *'over and over again'*. It is apparent that some phenomena experienced as a CHN can be deeply distressing, memories linger and for some they think the memories will never be forgotten. An emotional residue is left with a sense of haunting seems to prevail for these nurses. This leads me to consider if these nurses are at risk of vicarious traumatisation. Although my dissertation cannot extend to exploring this possibility in detail, it is worthy of commenting that Clark and Gioro, 1998; Sambo, 2008 and Bush, 2009 recognise that nurses involved in end of life care situations are not immune from experiencing vicarious traumatisation.

In contrast to what could be described as unfavourable experiences; the findings also show that hospice nurses recognise that the unfavourable experiences are part of a bigger aim. Pippa (115-123) spoke of her place of work, the aims and the environment in an almost idyllic manner. A fondness and proudness of the environment she worked within is present. Yasmin (258-259) comments upon how she enjoys caring for families. Beth (252-253) comments that the care her team gives to the families makes her very proud. At the heart of these comments is an overwhelming sense of care and dedication to the families they support.

It seems easy for the nurses to emotionally explore the positive side of CHN. Although the nurses can describe the traumas and disgust they encounter, exploring the impact on a personal and emotional level and relating these experiences to the impact this has on their own mortality appears to be challenging and intimidating for them representing an avoidance or denial. This consideration would be in keeping with Gwen's (173) comment that for some nurses talking about feelings can "*open a can of worms*". Beth (320) describes experience when she witnessed staff becoming very distressed when they were asked about their emotions and how they coped she comments "*it was really traumatic*". In both of these examples the nurses spoke from a third person perspective. Could the lack of first person speak reflect an avoidance of looking at their feelings but be represented and shared through third person speak? Is this representative of a death related anxiety? Hadders comments "The aspects of the dead body which may result in distance and aversion are tied to visual, tactile, olfactory as well as audible experiences" (2007 p.213). Does the distance and aversion that Hadders talks of relate to emotional distance and aversion, and if so, was this avoidance present in the interview room? As Papadatou (2001) suggests, is it that the nurses suppress their emotions for fear of showing

their vulnerabilities? Anderson, Ewen and Miles (2010) suggest that emotional expression is precluded due to professional expectations. Perhaps as Hopkinson, Hallet and Luker, 2005; Van Hooft, 2003 (as cited in Tschudin, 2003) suggest avoidance of feelings enables nurses to continue to work with empathy and compassion.

Although my analysis points to a sense of avoidance for most of the participants in discussing personal mortality in significant emotional depth, the data showed a significant link between being a CHN and the mortality of the nurse's own children. For two nurses, Beth (66) and Pippa (247-250) their child's mortality initially came to mind more than their own mortality. Although Yasmin is not a mother she feels that once she has children she will find her role as a CHN far more difficult. The nurses talk of comparing similarities between the child in the hospice and their own child. Gwen (17-42) talks of one instance where she identified similarities between a child she cared for at the hospice and her own son which caused Gwen significant grief. There was a sense from Gwen that there was nowhere for her to grieve for the potential reality that this could have been her son and the unfairness of the illness. It felt as though Gwen was not entitled to grieve for the losses she saw within the child she cared for and also to grieve the potential for her son to be affected by a similar illness. It could be suggested that the emotional responses that Gwen experienced hold some similarities to disenfranchised grief.

Fromm (1985, p.50-51) explains that "...motherly love has been considered as the highest kind of love...which wants nothing for oneself". Therefore perhaps for some nurses to consider and discuss one's own mortality would be selfish or superficial as the loss of their child is far more significant than the loss of their own life? Perhaps because CHN's witness children die so regularly the reality of child death is deeply

present within them, and therefore the vulnerability of their own child's mortality is overtly present? I also wonder if it could be argued that talking of their child's mortality is a method of avoidance in looking at their own mortality?

The use of metaphorical language to describe how CHN cope was evident and could be suggested as being another avoidance method "You put a hat on" (Beth, 69), "it is beneficial to be able to put it away." (Yasmin, 208), "you detach yourself" (Gwen, 79). Indeed the mechanism of coping can be useful, but they are also suggestive of emotional distancing, a protection from the powerfulness of death, a dominant choice to favour the containment of the true emotions attached to their work.

It seems that the emotional impact of CHN is significant. The frequency of death is high, the encounters experienced with the child can be harrowing and the memories of the experiences have the potential to linger. Feelings of guilt, anxiety, sadness and frustration are some of the feelings experienced by the CHNs interviewed. The feelings evoked through the intensity work described by the participants has led me to consider if these nurses are at risk of vicarious trauma and disenfranchised grief. Taking into account these factors leads me to consider one of the aims I set out to achieve; if access to counselling would be beneficial to the nurses? The research clearly shows that most of the participants think they would find a counselling service beneficial. As McLeod (2009) explains, counselling can impact positively on self-awareness, self-acceptance, self-actualisation as well as offering enlightenment and empowerment to a client. These areas of personal growth could be considered as being useful process for the nurses to engage with, should they wish to in order to support them in their role as a CHN. However, in hindsight I also feel that this aim was somewhat naïvely considered as so many factors need to be considered on an individual basis. Factors such what support does the nurse have access to within the

hospice; the most appropriate type of counselling approach; if the counselling would be accessible through an employee assistance programme; and the clients readiness to engage in a counselling process.

CHAPTER 6: CONCLUSION

6.1 Limitations

This research is part of the requirement for a Masters Degree in Clinical Counselling and therefore is limited by time, resources and experience. As my research is a small scale study the findings cannot be generalised to a larger population. My research is UK based only and represents the experiences of four female participants from two different CHs. Due to my sampling method and aim of the research, other hospice workers such as physiotherapists, play specialists, cooks and volunteers were not given a voice as to how working in a hospice impacts their thoughts and feelings surrounding personal mortality. The request for the participants to have a minimum of 2 years' experience working in a CH is also a limiting factor. This criterion perhaps assumes that those without two years' experience have had no relevant experiences, which I recognise is not the case. My reasoning for this criterion is based on the fact that those with two years' experience plus, are more likely to have had a higher number of exposure to experiences that are relevant to my research and therefore are more likely to have reflected on these experiences.

McLeod (2011) suggests that the most valid research is achieved through a repeated cycle of data emersion and analysis, as time does not allow this, only one cycle was possible. This coupled with my inexperience as a researcher creates limitations in the development of the emersion process. Denscombe (2010) comments that one methodology prevents the process of triangulation occurring. When more than one methodology is introduced more than one perspective is generated. Denscombe

claims that this process improves accuracy and can provide the researcher with a fuller picture of the focus area.

6.2 Outcomes

The outcomes of this study indicate that aspects of the CHNs role do impact upon nurse's thoughts and feeling surrounding their mortality. The emotional impact of this proves to be positive for some nurses whilst negative for others.

There was an awareness of the finiteness and fragility of life as well as an appreciation and respect for life. Some nurses found that being exposed to death and dying in its rawness enabled them to make plans for their death and to communicate these wishes with loved ones. The majority of nurses talked of the satisfaction and fulfilment they gained from being a CHN and commented that this feeling enables them to continue in their role. For other nurses the 'trauma' of their experiences remains with them and some believe the memories will never be forgotten. Feelings of disgust, identification and incompetence prevail and it is in these emotionally demanding times the importance of supportive colleagues and family is evident. The majority of nurses commented that they felt a counselling service would be beneficial in supporting them to process their experiences as a CHN and when required to explore thoughts and feels surrounding their own mortality.

6.3 Further Research

Further research into the link between CH nursing and personal mortality wishes would be helpful in creating a solid body of literature within this field. Deeper research into the link between CH nursing and vicarious trauma would also be worthy of exploration. This may help to establish those CHNs who are more likely to be at risk of vicarious traumatisation in relation to the unique role of the CHN. Research into hospice nurses who have been witness to what they perceive as 'traumatic' experiences and whom have engaged in counselling as a result of these traumas may be another area worthy of research. Research in this area may reveal more insight into the emotional impact of these experiences, the effectiveness of counselling for hospice nurses and whether this is an area of support which could be offered to staff in the CH setting.

6.4 Implications for Practice

As a nearly qualified counsellor with a family support practitioner role in a CH I have become further aware of the importance of self-care within a CH environment. Team support seems to be vital in fostering resilience. It can become very easy for nurses and other healthcare professionals within the CH to become complacent of the emotional labour that is attached to providing high quality care to children and their families. I feel drawn to encourage nurses to talk of their workplace experiences, make them aware of the benefits of counselling and signpost nurses to counselling agencies accordingly.

6.5 Recommendations

From the research undertaken for this study I feel there are a number of recommendations that should be considered by CH managers when reviewing the emotional care of their nurses. The study has revealed that some nurses do consider their personal mortality as a result of the experiences they encountered working as a CHN. The study has also revealed a plethora of profound experiences which have left nurses with powerful images and feelings. It therefore feels important that managers consider what forums are available for staff to explore their feeling and if what is offered is adequate and suitable to staff needs. It seems from the study that most CHNs attend debriefs following the death of a child, however it seems that the nurses experience of these forums is that they focus on the clinical appraisal of the case. The results of the research have led me to believe that consideration of how CHNs can access a counselling service if required is paramount. This could be provided directly through the hospice, or through employee assistance programme or by simply providing a list of appropriate BACP registered counselling services to CHNs. It would be important to ensure that all recommended counsellors would be members of the BACP to ensure adequately trained, ethical counsellors are selected.

6.6 Summary

The experiences of working in a CH have been demonstrated as wide ranging and impactful. The research has shown that CHNs do have a strong awareness of their own mortality. Working as a nurse in a CH exposes these individuals to the hidden

side of hospice work, death and dying and therefore increases ones knowledge of this area. It seems that this insider knowledge does have a significant impact upon how some nurses think about their own mortality; however it has been recognised that other influences outside of the hospice also contribute to the nurses' awareness of their own mortality.

This small, time framed study has its limitations but does offer an insight into the authentic experience of a CHN. The literature in this area is minimal and therefore I hope this study is of interest to those interested in supporting the emotional needs of nurses who work in CHs.

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APPENDIX 1: Audit Trail

Table of Possible Search Words Relating to Research Question

Impact	Nurse	Children's Hospice	Thoughts	Feelings	Personal	Mortality
Stress	Registered nurse	Rest home	Cognitions	Awareness	Intimate	Loss of life
Effect	Sister	Care home	Attentions	Senses	Own	Death
Wellbeing	Nurse practitioner	Place of death	Reflections	Impressions	One's	Dying
Resilience	Professional	Care setting	Understandings	Reaction	Individual	Ending
Significance	Carer	Hospital	Contemplations	Sensitivities	Private	Transience
Influence		Funeral homes	Beliefs	Emotions	Your	Humanity
		Palliative care settings	Concepts		Endemic	Impermanence
		Cold room				Existential
		Last offices				Mortal
		Bereavement suite				Death awareness
		Mortuary				
		Morgue				

Table of Databases and Journals Searched Search Terms and Articles Found

Database/Journal	Search Terms	Articles found
CINAHL Plus with full text	Mortality AND hospice nurses Nursing AND hospice AND mortality Hospice AND nurse AND death: Personal mortality AND nurses AND hospice Occupational stress AND hospice Death anxiety AND nurses Nursing AND debrief	<ul style="list-style-type: none"> • General nurses' experiences of end-of-life care in the acute hospital setting: a literature review • An investigation into the perceived stressors for staff working in the hospice service • Nurses in cancer care—Stress when encountering existential issues • Everyday death: how do nurses cope with caring for dying people in hospital? • Emergency and palliative care nurses' levels of anxiety about death and coping with death: A questionnaire survey • How Death Anxiety Impacts Nurses' Caring for Patients at the End of Life: A Review of Literature

		<ul style="list-style-type: none"> • A comparative study of death anxiety in hospice and emergency nurses • Debriefing: A valuable component of staff support • Phase 1 of an investigation into the levels of stress in United Kingdom hospice services
PSYArticles	Hospice nursing Death AND nursing Death anxiety	<ul style="list-style-type: none"> • Effectiveness of a counseling support program for hospice nurses. • Don't Fear the Reaper: Trait Death Anxiety, Mortality Salience, and • Occupational Health A quiet ego quiets death anxiety: Humility as an existential anxiety buffer
International Journal of Palliative Nursing	Staff stress AND hospices Emotional safety Children's hospices Death AND dying Cold room Last offices	<ul style="list-style-type: none"> • An investigation into the perceived stressors for staff working in the hospice service • A study of staff support mechanisms within children's hospices • Emotional safety in the workplace: one hospice's response for effective support • Coping strategies, emotional outcomes and spiritual quality of life in palliative care nurses • A study of staff support mechanisms within children's hospices • Nurses' responses to death and dying: a need for relentless self-care • Death anxiety amongst nurses • Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child • Families' experiences of the last office of deceased family members in the hospice setting • When last offices are more than just a white sheet
PubMed Database	Death anxiety nurses Hospice workers death	<ul style="list-style-type: none"> • How death anxiety impacts nurses' caring for patients at the end of life: a review of literature. • Caring for Dying Children: Assessing the Needs of the Paediatric Palliative Care Nurse • The psychological experience of hospice workers during encounters with death.
Wiley Online Library		<ul style="list-style-type: none"> • Resilience and well-being in palliative care staff • A comparative study of death anxiety among hospice and emergency nurses
Google Scholar	Professional, death and dying Stress hospice Stress of working with those who are dying Nursing the dying Caring for the dying in hospitals/hospices	<ul style="list-style-type: none"> • Stress and coping in hospice nursing staff: The impact of attachment styles • Working with dying people: Crises and compensations • Working with dying: Crisis and compensations • Professional tears: developing emotional intelligence around death and dying in emergency work • Phenomenological study of nurses caring for dying patients • Caring for Dying and Meeting Death: Experiences of Iranian and Swedish Nurses • Everyday death: how do nurses cope with caring for dying people in hospital? • Caregivers in death, dying and bereavement

		situations • Care of the dying patient: The last hours or days of life
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Many other articles found for this dissertation were achieved through snowballing.

APPENDIX 3: Letter to Children's Hospices



(Hospice address)

Dear (Name – Head of Care)

(Date)

I am a third year student studying for an MA Clinical Counselling qualification at the University of Chester. I also have a long working history at Claire House Children's Hospice, and presently I am employed at Claire House as a family support practitioner.

I write to ask for your consideration in advertising for participants to take part in my MA Clinical Counselling dissertation in your hospice. I am looking for participants who are nurses or assistant care team members, who meet my research inclusion criteria of being a Nurse currently working in a children's hospice, who works a minimum of 18 hours or above on a weekly basis and who has a minimum of two years working experience in a children's hospice. They must be experienced in working with children in the palliative/end of life/care after death stages, be fluent in English, and be aged over 18 years. They need to be willing to answer a set of questions through the means of an audio recorded interview. The interview will last approximately an hour and will take place in a mutually convenient venue. The interview questions will be based around my research title:

Personal Mortality: An Exploration into the Impact of Working in a Children's Hospice on Nurses and Assistant Care Team Members.

There are a number of potential benefits to this research. Nurses and assistant care team members will be given a voice as to the emotional demands of their role, which will further inform hospices and other similar organisations of how working in the field of death and dying impacts on care staff. I also aim to explore if a staff counselling service would be beneficial in children's hospices. My literature review revealed that this area of enquiry appears to be both under-researched and that the impact of such work is underestimated. I feel passionate that in order for children's hospices to deliver high quality care to the children and young people they look after, more research needs to take place in addressing the impact that these roles may have upon staff members.

Enclosed are a number of posters advertising my research study. I hope you are able to place these in your staff room or communication book, or anywhere else you see appropriate. I have also enclosed a CD with an electronic version of the advert should you feel that e-mail may be an effective way to communicate with your team of nurses and assistant care team members.

Following distribution of the advert, it is the responsibility of the interested participant to contact me directly to register their interest in the study. I will then communicate with the participant in a confidential and ethical manner to issue further research interview information.

I would greatly appreciate if you could kindly respond to this letter by emailing: @chester.ac.uk to inform me if you will be advertising my research in your hospice.

Thank you for your time in reading this letter, if you have any questions please feel free to email me or phone me on.

Yours sincerely,

Catherine S R Livesey

APPENDIX 4: Research Advert

Personal Mortality: An Exploration into the Impact of Working in a Children's Hospice on Nurses and Assistant Care Team Members

I am a trainee counsellor studying at the University of Chester, carrying out research to exploring the depth to which nurses and Assistant Care Team members contemplate personal mortality. I am looking for participants to take part in my research who meet the following criteria:

- A nurse or assistant care team member/health care assistant currently working in a children's hospice.
- Working a minimum of 18 hours on a weekly basis.
- Have a minimum of two years experience in a children's hospice.
- Experienced in working with children at end of life and care after death.
- Have not experienced a personal bereavement in the last two years.
- Have not been diagnosed with a life shortening/terminal illness.
- Fluent in English.
- Aged over 18 years.

Participation in the research would involve an hours long, audio- recorded interview in a confidential setting.

If you would like to participate in this research please take a tear off strip and contact me via email or phone for further information

Catherine Livesey

Thank you

Catherine:



APPENDIX 5: Research Information Sheet

Study Title: Personal Mortality: An Exploration into the Impact of Working in a Children's Hospice on Nurses and Assistant Care Team Members

About the researcher

I am a third year post graduate student at the University of Chester studying for an MA in Clinical Counselling. In addition to my studies, I work in a local children's hospice as a family support practitioner.

The aim of the research

Currently, there is limited research into nurses' and assistant care team members' authentic lived hospice experiences, and how these experiences impact thoughts and feelings surrounding their own mortality. Therefore, the aim of this research is to explore the depth to which nurses and assistant care team members contemplate personal mortality.

If I wish to take part, what will happen?

To take part in the research, you must fulfil the following criteria:

- Be a Nurse currently working in a children's hospice.
- Be working a minimum of 18 hours or above on a weekly basis.
- Have a minimum of two years working experience in a children's hospice.
- Be experienced in working with children in the palliative/end of life/care after death stages.
- Be fluent in English.
- Be aged over 18 years.

If you decide that you would like to take part and you meet the inclusion criteria, participation in this research would involve an hour's long audio recorded interview held in English. This would take place in a confidential setting at a time and place convenient you. Before the interview starts, I will ask you to sign a consent form (1) stating that you are willing to take part in the interview. In the interview, the following questions will be explored:

- What does the term 'personal mortality' mean to you?
- Please describe any hospice experiences that have led you to question your own mortality?
- What thoughts and feelings were you left with following this experience?
- How have these experiences impacted upon your thoughts and feelings surrounding your own mortality?

- Working in a children's hospice can be emotionally demanding, what personal coping strategies do you have in place to help you to continue your role?
- Research shows that many hospices hold debriefs and 1:1's as a form of staff support in children's hospices. What are your experiences of these forums in addressing your personal mortality needs?
- What would your view be on the provision of a counselling service for staff to explore some other their personal mortality issues?
- Do you have any closing comments you wish to make?

You are welcome to prepare some thoughts and answers prior to the interview if you wish, although this is not obligatory. Straight after the interview there will be an opportunity for you to debrief allowing for an opportunity for you to reflect on the interview process. The debrief will not be audio recorded and is not mandatory.

Following the interview, I will transcribe the audio-recording, and this will become my data after you give consent for the data to be used in the research. A copy of the transcript will be sent to you to check for accuracy. I will then require you to sign a second and final consent form (2) stating that the data can be used in the research. Once final consent has been given and the analysis begins, you will not be able to withdraw or change the material, as the data will have added into the group data set, and it will no longer be possible to isolate it.

The data, and that of other participant's, will be analysed to identify themes. Following this I will write up the findings. I will use verbatim extracts from the transcript, but will ensure that anonymity is created through use of a pseudonym or by using a code (e.g. F3). The results of my research will form part of my MA dissertation which will be submitted to the University of Chester who will keep a copy. The results may also form part of other works which are put forward for publication.

Is there a cost involved in taking part?

There are no cost implications for participants taking part in the research.

What are the potential advantages of taking part?

As a participant, you will be given a voice as to the emotional demands of your role. You will be part of a study that will further inform hospices and other similar organisations how working in the field of death and dying impacts care staff.

Are there potential disadvantages in participating?

There is a risk that exploring this sensitive topic area may bring up unexpected feelings for you. If this were to happen I would ensure that I issued you with a list of free, appropriate counselling support agencies where possible. I would also ensure

that you were able to access a list of counsellors registered by the British Association for Counselling and Psychotherapy.

Participant's rights

Participants have the right to be fully informed about the research process prior to agreeing to participate. Participants have the right to modify or withdraw their consent from the research at anytime before data analysis has begun. Withdrawal from the research will not require explanation and choice of withdrawal will be respectfully accepted and acted upon immediately. Participants should not fear reprisal or penalties for withdrawal.

Data Protection and confidentiality

Following the interview the audio recordings will be copied onto my laptop and will be password protected. The original dictaphone recording will then be deleted. Transcripts will also be stored on my laptop and again will be password protected. Paper copies of the transcript may be used, but when not in use, paper copies will be securely locked away. Passwords will be saved under a pseudonym so participants cannot be recognised from the file name. All data will be also stored on a pen drive that will be kept safe in a locked drawer. Pseudonyms or codes will be used throughout the research process in order to protect participant anonymity. A hard copy of the data will be kept secure for five years in line with the University of Chester's regulations. All information will remain confidential unless this is restricted or prevented by law.

Ethics

Throughout the research process I will be abiding by the British Association for Counselling and Psychotherapy Code of Practice and Ethical Guidelines as well as the University of Chester's Research Governance Handbook. Protecting my participants from any unnecessary harm or loss during the research process is of utmost importance. Before being able to carry this research out I have submitted a research proposal and have gained ethical approval from the University of Chester to undertake this research. Throughout the process I will be working with my supervisor, Dr Peter Gubi who will supervise me in monitoring ethical responsibilities.

What if I am unhappy with the process?

If you are unhappy with any part of the research process or in the case of an adverse event, I would hope you would be happy to contact me in the first instance. (My details can be found at the bottom of this information sheet.)

In the second instance my research supervisor Dr Peter Gubi is contactable:

Email: Telephone:

In the third instance the Head of Social Studies and counselling, Meriel D'Artrey is contactable:

Email:

Telephone:

Please do contact me if you have any further questions regarding the research. My details can be found on the bottom of this information sheet. **Thank you**

APPENDIX 6: Participant Questionnaire

Study Title: Personal Mortality: An Exploration into the Impact of Working in a Children's Hospice on Nurses and Assistant Care Team Members

Thank you for your interest in taking part in this research.

Please fill in this form and send back to me via email: [@chester.ac.uk](mailto: @chester.ac.uk)

Name:

Address:.....

Contact Telephone number:

Contact E-mail:

Name of the Children's Hospice you work for:

Hospice role:

How long have you worked in this role?.....

Please circle your age group: 18 – 25 26 – 35 36 – 45 46 – 55 56 – 65 66 +

Have you experienced a significant personal bereavement in the last 2 years?

Yes No

Have you been diagnosed with a life shortening/terminal illness?

Yes No

Thank you for filling in the questionnaire.

APPENDIX 7: Participant Profiles

Name	Hospice role	Time worked in this role	Age group	Significant personal bereavement in last two years	Diagnosis of a life shortening/terminal illness
Pippa	Team Leader	3 Years	36-45	No	No
Beth	Senior Sister	17 Years	46-55	No	No
Yasmin	Senior Nurse	2 ½ Years	26-35	No	No
Gwen	Team Leader	15 Years	36-45	No	No

The names in this table are pseudonyms to protect participant's identities.

APPENDIX 9: Research Consent Form 2

M. A. in Clinical Counselling Research University of Chester

Consent Form: Audio/Digital Recording of Interview

Study Title: Personal Mortality: An Exploration into the Impact of Working in a Children's Hospice on Nurses and Assistant Care Team Members

Ihereby give consent for the details of a written transcript based on an audio/digital recorded interview with me and..... to be used in preparation and as part of a research dissertation for the M.A. in Clinical Counselling at the University of Chester. I understand that my identity will remain anonymous and that all personally identifiable information will remain confidential and separate from the research data. I further understand that the transcript may be seen by Counselling Tutors and the External Examiner for the purpose of assessment and moderation. I also understand that all these individuals are bound by the British Association for Counselling and Psychotherapy Ethical Framework for Good Practice in Counselling and Psychotherapy.

I understand that I will have access to the transcribed material and would be able to delete or amend any part of it. I am aware that I can stop the interview at any time or ultimately withdraw the interview, without giving a reason or explanation, at any point before data analysis has begun. I have the choice to withdraw without explanation and my withdrawal will be respectfully accepted and acted upon immediately. I should not hold fear of reprisal or penalties because of my withdrawal.

Upon satisfactory completion of the M.A. in Clinical Counselling the recording will be securely destroyed. The transcripts and related data will be securely stored for a period of five years, by me, the researcher, and then destroyed.

Excerpts from the transcript will be included in the dissertation. A copy of the dissertation will be held in the Department of Social Studies and Counselling and may be made available electronically through Chester Rep, the University's online research repository. Without my further consent some of the material may be used for publication and/or presentations at conferences and seminars. Every effort will be made to ensure complete anonymity.

Finally I confirm I have read and understood the attached Information Sheet and was given the opportunity for further explanation by the researcher. I believe I have been given sufficient information about the nature of this research, including any possible risks, to give my informed consent to participate.

**Signed [Participant
Name- Please Print**

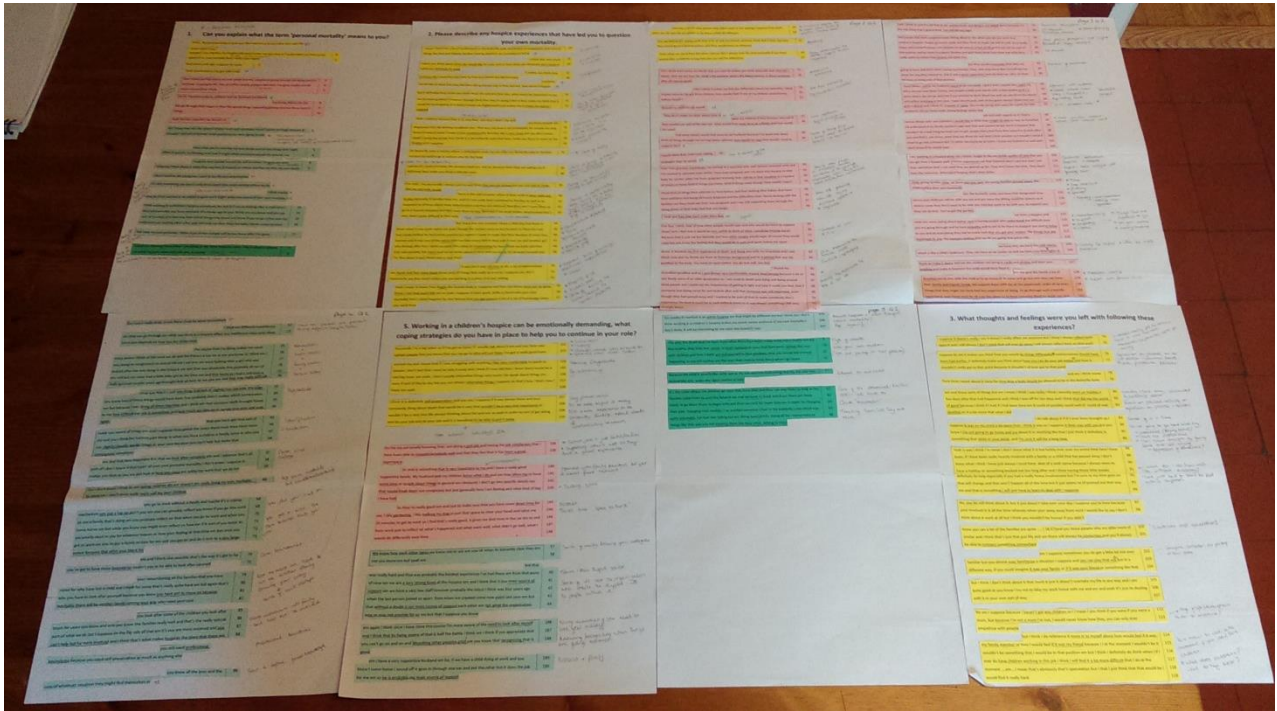
Date

**Signed [Researcher]
Name - Please Print**

Date

APPENDIX 10: Interview Schedule

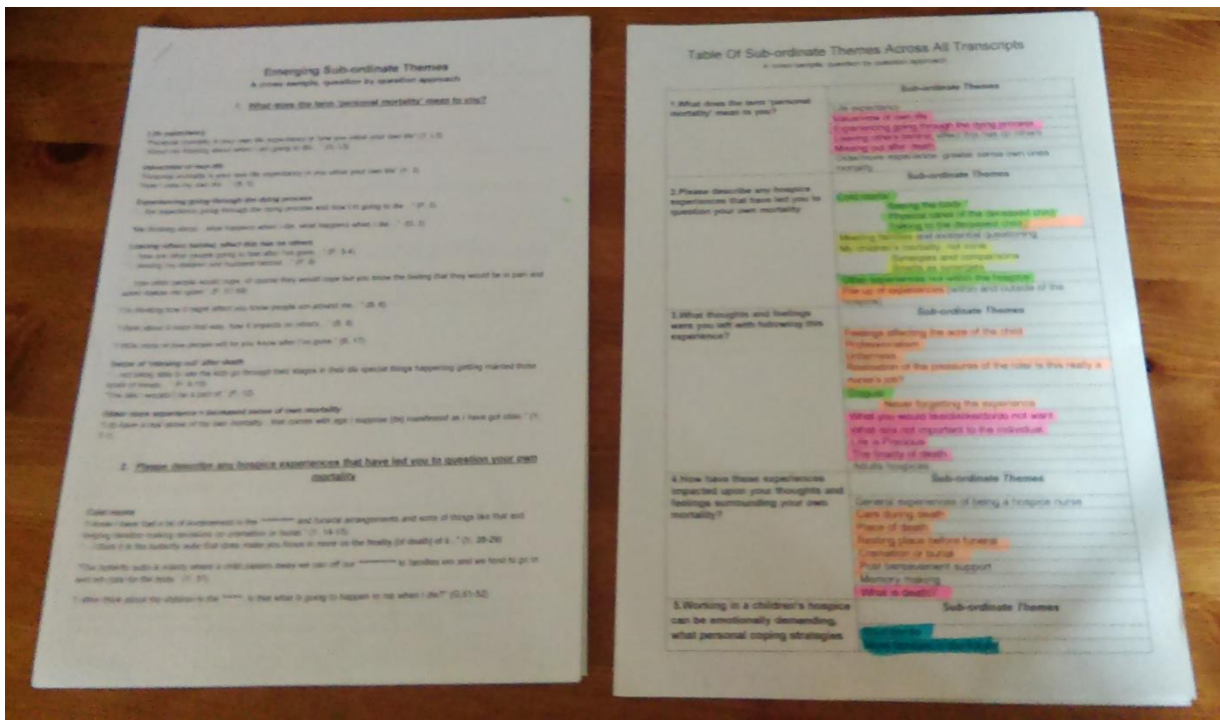
1. What does the term 'personal mortality' mean to you?
2. Please describe any hospice experiences that have led you to question your own mortality?
3. What thoughts and feelings were you left with following this experience?
4. How have these experiences impacted upon your thoughts and feelings surrounding your own mortality?
5. Working in a children's hospice can be emotionally demanding, what personal coping strategies do you have in place to help you to continue your role?
6. Research shows that many hospices hold debriefs and 1:1's as a form of staff support in children's hospices. What are your experiences of these forums in addressing your personal mortality needs?
7. What would your view be on the provision of a counselling service for staff to explore some other their personal mortality issues?
8. Do you have any closing comments you wish to make before the interview finishes?



Exploratory comments spreading over a number of questions.

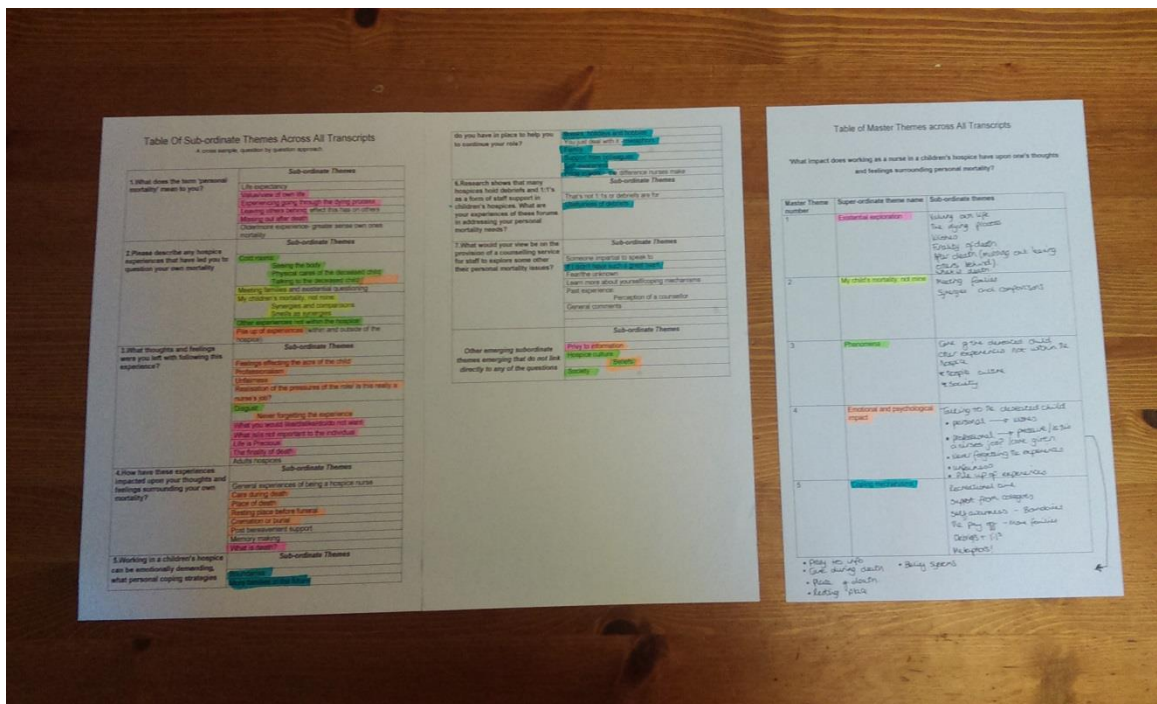


All transcripts and exploratory comments complete.



Left: Emerging sub-ordinate themes on a question by question basis.

Right: Whittling down of emerging subordinate themes to create master theme. The highlighted text shows where the master themes fall throughout all the transcripts. Each highlighted colour represents a proposed master theme.



Left: Proposed master themes.

Right : Creating titles for the master themes and clarifying sub-ordinate themes.

APPENDIX 12: Emerging Sub-ordinate Themes

A cross sample, question by question approach

1. What does the term 'personal mortality' mean to you?

Life expectancy

"Personal mortality is your own life expectancy or how you value your own life" (Y, L3)

"About me thinking about when I am going to die..." (G, L3)

Value/view of own life

"Personal mortality is your own life expectancy or you value your own life" (Y, 3)

"How I view my own life..." (B, 5)

Experiencing going through the dying process

"...the experience going through the dying process and how I'm going to die..." (P, 3)

"Me thinking about...what happens when I die, what happens when I die..." (G, 3)

Leaving others behind, effect this has on others

"...how are other people going to feel after I've gone..." (P, 3-4)

"...leaving my children and husband behind..." (P, 8)

"...how other people would cope, of course they would cope but you know the feeling that they would be in pain and upset makes me upset." (P, 57-58)

"I'm thinking how it might affect you know people em around me..." (B, 6)

"I think about it more that way, how it impacts on others..." (B, 9)

"I think more of how people will be you know after I've gone." (B, 17)

Sense of 'missing out' after death

"...not being able to see the kids go through their stages in their life special things happening getting married those kinds of things..." (P, 8-10)

"The bits I wouldn't be a part of." (P, 12)

Older/ more experience = increased sense of own mortality

"I do have a real sense of my own mortality...that comes with age I suppose [its] manifested as I have got older." (Y, 7-1)

2. Please describe any hospice experiences that have led you to question your own mortality

Cold rooms

"I know I have had a lot of involvement in the ***** and funeral arrangements and sorts of things like that and helping families making decisions on cremation or burial." (Y, 14-15)

"...I think it is the butterfly suite that does make you focus in more on the finality [of death] of it..." (Y, 28-29)

"The butterfly suite is mainly where a child passes away we can off our ***** to families em and we tend to go in and em care for the body." (Y, 31)

"I often think about the children in the ***** , is that what is going to happen to me when I die?" (G,51-52)

"...when you're out in the normal world and you have nothing to do with things like this you wouldn't ever think ooohhh it will happen to me, this is what I am going to look like when I die, is my body going to go that colour and you just wouldn't think it..." (G,53-55)

Seeing the body

"There is the odd occasion where it really does get to you..." (Y, 40)

"...if the body's deteriorated that's very, that's quite difficult to deal with..." (Y, 43-44)

"There was one occasion where a little boy had been in there when it was quite warm em even though the coolers were on he had been in there for over two weeks before his funeral...it was not nice at all...a lot of deterioration em hands and feet were black..." (Y, 44-49)

"...we shouldn't have to see some of the things we see with dead children, how they look and blisters and things like that..." (G, 68-69)

"It's just not very nice, it's horrible, it's horrible and you do go home and think about it..." (G, 73)

Physical cares of the deceased child

"...we have to wash and dress them, we care for them daily em it might be changing their pad, changing their clothes... em doing handprints, doing all the mementoes and things like that..." (G, 62-65)

"I've washed someone's hair in the ***** which was quite traumatic, her hair was falling out..." (G, 65-66)

"...she continually leaked...and the dignity of the care one of the nurses went up in twos to change the sheets underneath her and the way this nurse just handled this little lump of jelly basically as if she was the most precious thing in world." (B,248-252)

Talking to the deceased child

"...still treating them like they were alive, talking to them..." (G, 67)

"...I always just try and think they are just asleep and you just talk to them like you normally would." (Y,39)

Meeting families and existential questioning

"I think every family that you care for makes you think about life and what's life about, what are we here for, what's the purpose, what's the bigger picture, is there anything after you've gone..." (P, 17-19)

My children's mortality, not mine

"Around my children, not myself" (P,23)

"They don't make me think about mine at all" (P, 27)

"I don't think it makes me feel any different about my own mortality. I think maybe more as I've got three children, how would I feel if one of my children passed away before myself." (P,19-21)

"...if my children became very sick if they needed em end of life care em how would that mean to us as a family and how would we cope." (P, 27-29)

"I don't think its em seeing children die em doesn't em really bring my own mortality to mind em ...really more so of my children." (B, 66)

"It's not so much myself, it's my children because my children are the most important people in my life so how would I feel if anyone of them needed end of life care cos I wouldn't want them to suffer, so having those ideas in my head really. What would be acceptable, what would not be acceptable, yeah definitely?" (P, 247-250)

Synergies/comparisons

"...the children that have had cancer or brain tumours or the ones that have been normal like your own children...you put yourself in their positions..." (G,10-11)

"The child is exactly the same age as my son, was into everything that my son was into, looked like him, wears the same clothes as him." (G,17-18)

"...its only as he's changed with his condition and he doesn't look like my son anymore, hes well into his condition now in that he's not normal at all that I feel able to look after him..." (G, 22-24)

"I've worked in neonatal units whilst I have been pregnant and I've been into theatre to take a baby for section...knowing that I will be in that situation in X number of weeks...what if things went wrong...how would I cope?" (P, 41-44)

"I think the hardest part things is when you have a child or a family come in who you can slightly identify similar things to your own because you can' help but make that comparison sometimes." (P, 45-48)

"...there will always be similarities and you'll always be able to connect something somewhere." (Y,101-102)

"...he was exactly the same age, everything about him, what his mum said about his life was just my son...it just really bothered me....I've never had a block like it before." (G,32-34, 42)

"...you almost over familiarise a situation I suppose and you can play that out in a different way, if you could imagine it was your family or if it was your friend..." (Y, 103-104)

"...I think I was doing and assignment on end of life care, em I em was looking after a girl, who was dying in the hospice, my sister had a baby girl at the time em and that because I had a still born baby over twenty years ago brought that all back to me...and that was really difficult." (B,25-30) ?

Smells as a synergy...

"...the smells, the smells...we used to have a certain air freshener ...and if you ever smelt it out in public you would think uuuggghh [cold room name] ...no its not nice." (G, 74-76)

Other experiences, not within the hospice

“...I was about nine and my family are from an Estonian background and it is tradition that you say goodbye to the body, you have an open casket, you go and visit, you kiss.” (P, 63 -65)

“...I was always very comfortable around dead people...I was used to death and dying being around, I could see the importance of getting it right and how it made you feel...and that someone was still important even though they had passed away...” (P,66-69)

Pile up of experiences both within and external to the hospice

“...I think I was doing an assignment on end of life care, em I em was looking after a girl, who was dying in the hospice, my sister had a baby girl at the time em and that because I had a still born baby over twenty years ago brought that all back to me...and that was really difficult.” (B,25-30)

3.What thoughts and feelings were you left with following this experience?

Feelings effecting care of the child

“... I couldn't go in and do medicines or I'd go in and I would have to face the other way, I couldn't look at him at all...” (G, 25-26)

“...when he was first diagnosed with his condition I couldn't look after him, it made me cry, I couldn't go near him...” (G,18-19)

“I'm a senior nurse and I felt awful...I'd sit in handover thinking please don't give me that child...” (G,19-20)

“...you do feel guilty because sometimes now I don't think twice about going into the ***** I just do it and it doesn't affect me at all but later on you think why doesn't this affect me anymore...there must be something...have I been doing it for too long?” (G, 89-92)

Professionalism

“In fifteen years he's the first one that ever affected me like that...your meant to be the one that can do anything because you're the senior person” (G, 26, 27,21,22)

“...I felt as if I shouldn't be feeling like that, I felt guilty that I felt like that because he's another child that should be able to care for, but I couldn't...I should be able to do my job.” (G,40-42)

Unfairness

“Upset, really really upset that it can happen and angry as well for this poor little boy what's happening to him.” (G, 37-38)

Realisation of the pressures of the role/ Is this really a nurse's job? Reflection on the role

“I was doing all three together...that occasion really brought home to me how difficult our job is sometimes and how much we take on as nurses em over and over again.” (B, 35-36)

“...I do think sometimes here we do have to see too much here, they have been here for so long and I don't know, its just not very nice.” (G,56-57)

“...who else has to do things like that in their job...” (G, 85-86)

Disgust

“...it was one of the worst we have had to deal with...I think we both felt a little bit traumatised...that was possibly the worst...it was not nice at all...” (Y,44-50)

Reflection

“ I think I will always reflect back on it...I don't think that will ever go away...” (Y,74-75)

“It makes you think how you would do things differently...how you can do your job better...” (Y, 76-77)

What you would like/dislike/do/do not want

“I think that very much makes you think about what you would like for your own or how what you definitely don't want or what you definitely do want” (Y, 15-16)

“It just makes me aware I suppose” (Y, 22)

Awareness that life is precious

“It makes you think how precious life is ...” (Y, 17-18)

“...it just reinforces the fact that life is very short and you don't know what's around the corner.” (Y,27-28)

“...it shows how fragile the human body is...an how once your gone your gone, that there's not much left, so yeah I suppose it does spark, strike a chord with your own mortality, that's what happens its very factual...” (Y,55-57)

“...and what's to say that it won't happen to me...” (G,31)

“Upset, really really upset that it can happen..” (G,37)

“... you never know when you're going to die or need palliative care...its good to plan beforehand...” (P, 211-212)

What is/is not important to you

“It definitely make you think about the end and how you, what would be important to you.” (Y, 20)

“For me I see palliative care and death and dying as a positive thing not a negative thing and that it is important to think about what is important to you, what your thoughts and feelings are about death and dying...” (P, 209-211)

Death is final, the end

“Yeah I suppose, because [death] is, it's very final and that's that's the end.” (Y, 24)

“...it's the one thing that is guaranteed, you will die one day.” (P, 75-76)=

Adult's hospice

“...maybe if I worked in an adults hospice em that might be different em but I think em I don't think working in a children's hospice makes me overly aware of my own mortality I don't think...” (B, 105-107)

4.How have these experiences impacted upon your thoughts and feelings surrounding your own mortality?

General experience of being a hospice nurse

“...working in a hospice gives me a better insight to the em better quality of care...a better experience...” (P, 109-110)

“...not that hospitals don't care but that's not their specialism that's not what they are geared up for, they don't have the time, they don't have the resources, whereas a hospice, that's their niche” (P, 110-112)

“...knowing all the stuff about end of life...in that respect, yes, it's sort of made me sort of think right well, I know exactly what I would want at the end of life.” (B,143-145)

“I think well you can't really dwell on it too much because you don't know what is going to happen at the end...” (Y, 269-270)

“I suppose out of amongst my friend and family I suppose I do know what I would want and maybe they have not given it a second thought...” (Y, 262-263)

“For me I see palliative care and death and dying as a positive thing not a negative thing and that it is important to think about what is important to you, what your thoughts and feelings are about death and dying and get it straight in your head because you never know when you're going to die or need palliative care...it's good to plan beforehand...” (P, 209-212)

Care during death

“Time, giving families time, we have one-once care...giving families private space, the children have their own bedroom, the sitting room...visitors come...you've got the garden... people who understand the difficult time you are going through to have empathy, to be there to support you and to listen to you, to make sure you get your wishes, the things that are important to you, the memory making...” (P,115-123)

“...it does definitely make you think what you would like at the end and what you wouldn't like and how a good death should be...” (Y, 126-127)

Place of death

“...if I had a serious illness and I was palliative I would like to think that I might be able to stay at home...I wouldn't mind if I had to go into a hospice but I'd rather obviously be at home...” (P, 66-102)

Resting place of the body before the funeral

“...we have the cold rooms which is like a child's bedroom...we have nice little lights in there to make it starry and em the children can bring in cards and photos and their own bedding.” (P,125-127)

Post bereavement support

“We support them with em all the paperwork, order of services, things that they might not of had any experience of doing...” (P, 130-131).

Cremation/burial

“...I want to be cremated, I don't want a burial site, I want my ashes to be thrown over Moel Famau ...I hate church yards with all the gravestones I think they are a waste of space...you could use up that space for a park for kids to play in...” (P,91-95)

“...I tell him about organ donation, I want this going, I don't care what they take, they can have anything they want.” (P,170-171)

“...I've changed my undertaker that I was going to have...we have always had one family undertaker, we've got an absolutely brilliant undertaker at work...he just cares so much about what he does.” (B139-142)

“...I think I will probably do my own order of service before I died...I constantly think about what hymns I'm going to have and who's going to say what and how many people will be crying.” (G, 101-104)

“You see the way we do it, so we do it really really well, really well and then you think back to the way it has been done with members of your family, when it’s not been done so well...” (G,115-117)

“...I just really wish that I am treated the way that we treat the children here.” (G, 117-118)

“...both my nans were in immense pain...one of them was by themselves...someone had found her in the morning...she died by herself in pain...” (G,120-123)

“...our children here are never by themselves when they die, the family is all around them...if they want to go to Chester Zoo we try and do that for them and make memories...even the ***** just to think you could be in a place like that and not be in a fridge mortuary.” (G, 123-126)

“People caring as much when you die as they do when you are alive” (G,128)

Memory making

“...maybe a little park bench with a little plaque so it’s a nice place where you can go and visit if you wanted to think about me and you can sit on the bench and reflect and have a nice view...” (P, 92-94)

What does being dead mean

“...this is going to sound really harsh and crass... I think once I’m dead I’m dead and I’m not going to feel anything, I’m not going to know, if there’s a spirit I’ll have my own, but I don’t think so...” (Y, 133, 136-137)

5.Working in a children’s hospice can be emotionally demanding, what personal coping strategies do you have in place to help you to continue your role?

********Boundaries***

“...you’ve got to have these boundaries haven’t you to be able to look after yourself...” (B, 75)

“...you still need professional boundaries because you need self-preservation as much as anything else.” (B, ?)

More families in the future

“... you have got to look after yourself, you have got to move on because inevitably there will be another family coming your way who need your care.” (B, 82)

Breaks, holidays and hobbies

“ I think I was lucky, I think I actually went on holiday a few days after that happened....I think it did me the world of good because I think if I had been here em [I] could well of dwelled on it a lot more than I did.” (Y,80-82)

“...I think having those little breaks definitely do help especially if you had a really heavy involvement...” (Y, 91-92)

“I’m sure as time goes on that [holiday falling] will change...and that is something that I will just have to learn to deal with I suppose.” (Y, 92-94)

You just deal with it – metaphors

“...you put a hat on...” (B, 69)

“...it’s just dealing with it in your own sort of way.” (Y, 106-107)

"I think it is definitely self-preservation...it is beneficial to be able to put it away." (Y,207, 210)

"You detach yourself a little bit and just pretend that they are still alive...when you are doing things you just chat to them like you usually do, it doesn't seem real really...it's just when you come out you think, oh god have I really done that..." (g, 79-83)

"...I am able to switch off I used to go home and get upset and I don't seem to do that as much anymore, I think you switch yourself off..." (G,133-134)

Family

"My husband and children know what I do...they allow me to have quiet time or to talk about things... have some down time... I like gardening, I like walking my dog..." (P,141-142)

"I have a very supportive husband...he is probably the main source of support." (G,189-191)

"...you do need stuff outside of work it's very difficult sometimes to switch off and I think that is an acquired art." (B,197-198)

Support from colleagues

"We have a very strong team...I think that is our main source of support, ...[the team] without a doubt is our main source of support for each other, not what the organisation may or may not provide for us..." (B,41-45)

Self-awareness

"I suppose it was on my mind a lot more than I think it was...it does stay with you...I'm not going to go home and cry about it...I just think it definitely is something that sticks in your mind....and I'm sure it will for a long time." (Y, 83-86)

"...you can always rationalise things, I suppose that's how I cope." (Y,157-158)

"I don't think you realise how demanding it is, you just carry on, it is only when something may happen that it hits you out of the blue and it just strikes you how demanding it can be." (G,271-273)

"You just have to learn to remember that they are not your family...they are nothing to do with you..." (G,94-96)

"...there are obviously occasions when you do lose a child here...it does feel like a little bit of a personal loss." (G,136-138)

"I've stopped going to funerals as well unless I feel that I need to... I don't get anything out of doing that now." (G,139-141)

"I have to protect myself now it's not my loss, you know it's not my family, I didn't love that child...I'm older and wiser now..." (G,149-150)

Pride in work – the difference nurses make

"...knowing that I am doing a good job and having the job satisfaction that I have been able to support someone well and that they feel it has been a good experience." (P,138-139)

"...the care that they give you know that makes me very proud to work with them..." (G,252-253)

“...I love being able to care for families, sometimes that can be at detriment to yourself...” (Y, 258-259)

6. Research shows that many hospices hold debriefs and 1:1's as a form of staff support in children's hospices. What are your experiences of these forums in addressing your personal mortality needs?

That's not what a debrief or 1:1 is for

“Usually when we have a debrief it's about that particular child and family and we talk about what went well, what didn't go so well, what you would do differently, how people were thinking and feeling at the time...” (P, 157,159)

“...I don't know if that's the place to do it...” (P, 164)

“I have 1:1s with my manager and I don't think it is something that I would really talk to my manager about...I would choose someone who is more of a friend...I'd be more inclined to speak to be husband about that...” (P, 167-169)

“...debriefs at work tend to be what went well and that's it really...” (B, 277)

“...they say 1:1 support is there but nothing formal in the form of supervision...” (B, 272-279)

“...I think it's a place to discuss the death and the care around that...the ones I've been to its all been about the child...” (G,156-159)

“I suppose there's some feelings but not really about your feelings, more about feelings for the family.” (G,161-162)

“...the debrief doesn't make me think of my own mortality really I think they make me think of my coping mechanisms but it doesn't I think make me aware of my own mortality, really just more of my own wellbeing...” (B, 280, 286)

Usefulness of debriefs

“...it depends on the group that you are with...are they willing to share those kinds of thoughts and feelings?...” (P,155-156)

“...it's a good learning tool...” (P,163)

“...it's helpful to listen to other people's views and again it's a good forum to sort of get things of your chest if you felt there was something that needed to be said...” (Y, 163-165)

“...it doesn't bother me talking about death and dying and how I think and feel about it, but I know other people aren't and I wouldn't want to put anybody else in a compromising position...” (P,174-176)

7. What would your view be on the provision of a counselling service for staff to explore some other their personal mortality issues?

Someone impartial to speak to

“I think that would be great, I think that would be a fantastic idea...I think to have someone professional who knows what you're going through and to be accessible. It would be fantastic to have that...” (P,191 -194)

“...it’s nice to have someone impartial to bounce ideas off to come to your own solutions...someone to listen to you... I think that would be fab.” (P, 198-199)

“...its good talking to your friends and family but they have their own thoughts, feelings and opinions ...so to have someone in a counselling role to talk to would be fab...” (P, 204-206)

If I didn’t have such a great team

“If I didn’t have such a big team and weren’t so supportive of each other, the maybe, I would definitely maybe looking for something else for another supportive mechanism or some form of counselling or something like that definitely something to try to help you cope.” (Y, 245-247)

“I have got really good colleagues here as well who I would talk to as well” (G, 290-291)

“I don’t think I talk about my own personal mortality needs other than say we had a conversation in the office the other day...it was an informal discussion...” (Y, 193-198)

Fear/the unknown

“I think some staff would worry that it would open a can of worms...” (G, 173)

it was really traumatic...they had never been asked that question, they had never been to consider how they coped with it...people found it really upsetting...we had done it differently it was quite simply because I think because it was a counsellor asking how we were...as opposed to how well we had done...” (B, 230-237)

Learn more about yourself/coping mechanisms

“I think it would be really, really useful for staff to look at their own feelings about how they cope with death of the children...some deaths effect you more than others...I think it would be really useful...” (B, 290-294)

“I definitely think it would be beneficial, I think a lot of people would benefit from it...” (Y, 191)

Past experience

“...we have tried it before in groups but it didn’t really work then...a counsellor used to come in...you could have one to one sessions...I didn’t get much out of it...she was very counselley and nodded...” (G, 177-289)

“...it was really traumatic...they had never been asked that question, they had never been to consider how they coped with it...people found it really upsetting...we had done it differently it was quite simply because I think because it was a counsellor asking how we were...as opposed to how well we had done...” (B, 230-237)

General comments

“I think it would probably be good, I think some staff would use it others wouldn’t...” (G, 172)

“I have said things that I have never really thought before, but I have not thought that I have thought about it, when you actually sit down and think about it, I think actually maybe it does, you do think about it a lot more than what you actually think you do.” (Y, 194-197)

Other emerging subordinate themes emerging that do not link directly to any of the questions

Privy to knowledge

“You get privy to a lot of knowledge when you work here...” (Y, 57-58)

“...being privy to a lot of information...we had a talk from an embalmer and she went into graphic detail...” (Y,129-130)

“Who else would get that sort of information...those sorts of things that not a lot of other people would be aware of I suppose.” (Y, 142, 147-148)

“...a lot of other people that didn't work in this setting I suppose they think when you die you die, em whereas we know a little bit different...” (P,58-59)

“You see behind the scenes...”(P,61)

“...as a nurse I suppose you don't necessarily see that much unless you are working in a care setting” (Y, 52)

“...you know all the pros and cons of whatever situation they might find themselves in...” (B, 96)

“...when you're out in the normal world and you have nothing to do with things like this you wouldn't ever think ooohhh it will happen to me, this is what I am going to look like when I die, is my body going to go that colour and you just wouldn't think it...” (G,53-55)

Children's hospice culture

“...when I worked in a hospital when a child died it was very much you took them from the ward and you took them to the mortuary and that was pretty much your involvement you had, whereas here it is very different your very hands on...” (Y,145-148)

Beliefs

“ I don't believe anybody should be in pain, regardless of where pain comes from...” (B,164)

Society

“...and it is sad that in our society today death and dying is not talked about because it's the one thing that is guaranteed, you will die one day...people feel so uncomfortable talking about it” (P, 75-78)

“...when you say you work in a children's hospice people go ooohhh really and they think its really sad and its not. It's a really happy and wonderful place...” (P, 78-80)

“I don't talk much about that with my husband...my husband says oh switch the plug, turn the plug off that sort of conversation...” (B,151-152)

Life stages/age

“I haven't got any children so mean...if you were a mum , because I'm not a mum, I'm not, I would never know how they, you can only ever empathise with people.” (Y,112-114)

“...I do definitely think when I, if I ever do have children, working in this job I think I will find it a lot more difficult than I do at the moment...” (Y, 116-119)

APPENDIX 13: Cross Sample of Master Themes

Master theme number	Master theme name	Sub-ordinate themes	Supporting lines in transcript
3	Mortality salience	<ul style="list-style-type: none"> Valuing own life 	<p><i>Awareness that life is precious</i> “It makes you think how precious life is ...” (Y, 17-18) “...it just reinforces the fact that life is very short and you don’t know what’s around the corner.” (Y,27-28) “...and what’s to say that it won’t happen to me...” (G,31) “...it shows how fragile the human body is...an how once your gone your gone, that there’s not much left, so yeah I suppose it does spark, strike a chord with your own mortality, that’s what happens its very factual...” (Y,55-57) “I think every family that you care for makes you think about life and what’s life about, what are we here for, what’s the purpose, what’s the bigger picture, is there anything after you’ve gone...” (P, 17-19)</p>
		<ul style="list-style-type: none"> Finality of death 	<p>“Yeah I suppose, because [death] is, it’s very final and that’s that’s the end.” (Y, 24) “...it’s the one thing that is guaranteed, you will die one day.” (P, 75-76) “...this is going to sound really harsh and crass... I think once I’m dead I’m dead and I’m not going to feel anything, I’m not going to know, if there’s a spirit I’ll have my own, but I don’t think so...” (Y, 133, 136-137)</p>
		<ul style="list-style-type: none"> After death 	<p>“...how are other people going to feel after I’ve gone...” (P, 3-4) “...leaving my children and husband behind...” (P, 8) “...how other people would cope, of course they would cope but you know the feeling that they would be in pain and upset makes me upset.” (P, 57-58) “I’m thinking how it might affect you know people em around me...” (B, 6) “I think about it more that way, how it impacts on others...” (B, 9) “I think more of how people will be you know after I’ve gone.” (B, 17) “...not being able to see the kids go through their stages in their life special things happening getting married those kinds of things...” (P, 8-10) “The bits I wouldn’t be a part of.” (P, 12)</p>

4	My child's mortality	<ul style="list-style-type: none"> • Synergies and comparisons 	<p>“Around my children, not myself” (P,23) “They don't make me think about mine at all” (P, 27) “I don't think it makes me feel any different about my own mortality. I think maybe more as I've got three children, how would I feel if one of my children passed away before myself.” (P,19-21) “...if my children became very sick if they needed em end of life care em how would that mean to us as a family and how would we cope.” (P, 27-29) “I don't think its em seeing children die em doesn't em really bring my own mortality to mind em ...really more so of my children.” (B, 66) “It's not so much myself, it's my children because my children are the most important people in my life so how would I feel if anyone of them needed end of life care cos I wouldn't want them to suffer, so having those ideas in my head really. What would be acceptable, what would not be acceptable, yeah definitely?” (P, 247-250) “I haven't got any children so mean...if you were a mum , because I'm not a mum, I'm not, I would never know how they, you can only ever empathise with people.” (Y,112-114) “...I do definitely think when I, if I ever do have children, working in this job I think I will find it a lot more difficult than I do at the moment...” (Y, 116-119)</p> <p>Synergies/comparisons</p> <p>“...the children that have had cancer or brain tumours or the ones that have been normal like your own children...you put yourself in their positions...” (G,10-11) “The child is exactly the same age as my son, was into everything that my son was into, looked like him, wears the same clothes as him.” (G,17-18) “...its only as he's changed with his condition and he doesn't look like my son anymore, hes well into his condition now in that he's not normal at all that I feel able to look after him...” (G, 22-24) “I've worked in neonatal units whilst I have been pregnant and I've been into theatre to take a baby for section...knowing that I will be in that situation in X number of weeks...what if things went wrong...how would I cope?” (P, 41-44) “I think the hardest part things is when you have a child or a family come in who you can slightly identify similar things to your own because you can' help but make that comparison sometimes.” (P, 45-48) “...there will always be similarities and you'll always be able to connect something somewhere.” (Y,101-102) “...he was exactly the same age, everything about him, what his mum said about his life was just my son...it just really bothered me....I've never had a block like it before.” (G,32-34, 42) “...you almost over familiarise a situation I suppose and you can play that out in a different way, if you</p>
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			<p>could imagine it was your family or if it was your friend..." (Y, 103-104)</p> <p>"...I think I was doing an assignment on end of life care, em I was looking after a girl, who was dying in the hospice, my sister had a baby girl at the time em and that because I had a still born baby over twenty years ago brought that all back to me...and that was really difficult." (B,25-30) ?</p>
1	Phenomena	<ul style="list-style-type: none"> Covert Phenomena 	<p>Privy to information</p> <p>"...working in a hospice gives me a better insight to the em better quality of care...a better experience..." (P, 109-110)</p> <p>"...not that hospitals don't care but that's not their specialism that's not what they are geared up for, they don't have the time, they don't have the resources, whereas a hospice, that's their niche" (P, 110-112)</p> <p>"...knowing all the stuff about end of life...in that respect, yes, it's sort of made me sort of think right well, I know exactly what I would want at the end of life." (B,143-145)</p> <p>"I think well you can't really dwell on it too much because you don't know what is going to happen at the end..." (Y, 269-270)</p> <p>"I suppose out of amongst my friend and family I suppose I do know what I would want and maybe they have not given it a second thought..." (Y, 262-263)</p> <p>"For me I see palliative care and death and dying as a positive thing not a negative thing and that it is important to think about what is important to you, what your thoughts and feelings are about death and dying and get it straight in your head because you never know when you're going to die or need palliative care...it's good to plan beforehand..." (P, 209-212)</p> <p>"You get privy to a lot of knowledge when you work here..." (Y,57-58)</p> <p>"...being privy to a lot of information...we had a talk from an embalmer and she went into graphic detail..." (Y,129-130)</p> <p>"Who else would get that sort of information...those sorts of things that not a lot of other people would be aware of I suppose." (Y, 142, 147-148)</p> <p>"...a lot of other people that didn't work in this setting I suppose they think when you die you die, em whereas we know a little bit different..." (P,58-59)</p> <p>"You see behind the scenes..."(P,61)</p> <p>"...as a nurse I suppose you don't necessarily see that much unless you are working in a care setting" (Y, 52)</p> <p>"...you know all the pros and cons of whatever situation they might find themselves in..." (B, 96)</p> <p>"...when you're out in the normal world and you have nothing to do with things like this you wouldn't ever think ooooo it will happen to me, this is what I am going to look like when I die, is my body going to go that colour and you just wouldn't think it..." (G,53-55)</p> <p>"...maybe a little park bench with a little plaque so it's a nice place where you can go and visit if you wanted to think about me and you can sit on the bench and reflect and have a nice view..." (P, 92-94)</p>
		<ul style="list-style-type: none"> Care of the child 	<p>Cold Rooms</p> <p>"I know I have had a lot of involvement in the ***** and funeral arrangements and sorts of things</p>

		<p>like that and helping families making decisions on cremation or burial.” (Y, 14-15)</p> <p>“...I think it is the ***** that does make you focus in more on the finality [of death] of it...” (Y, 28-29)</p> <p>“The ***** is mainly where a child passes away we can off our ***** to families em and we tend to go in and em care for the body.” (Y, 31)</p> <p>“I often think about the children in the ***** , is that what is going to happen to me when I die?” (G,51-52)</p> <p>“...when you’re out in the normal world and you have nothing to do with things like this you wouldn’t ever think ooohhh it will happen to me, this is what I am going to look like when I die, is my body going to go that colour and you just wouldn’t think it...” (G,53-55)</p> <p>Seeing the body</p> <p>“There is the odd occasion where it really does get to you...” (Y, 40)</p> <p>“...if the body’s deteriorated that’s very, that’s quite difficult to deal with...” (Y, 43-44)</p> <p>“There was one occasion where a little boy had been in there when it was quite warm em even though the coolers were on he had been in there for over two weeks before his funeral...it was not nice at all...a lot of deterioration em hands and feet were black...” (Y, 44-49)</p> <p>“...we shouldn’t have to see some of the things we see with dead children, how they look and blisters and things like that...” (G, 68-69)</p> <p>“It’s just not very nice, it’s horrible, it’s horrible and you do go home and think about it...” (G, 73)</p> <p>Physical cares of the deceased child</p> <p>“...we have to wash and dress them, we care for them daily em it might be changing their pad, changing their clothes... em doing handprints, doing all the mementoes and things like that...” (G, 62-65)</p> <p>“I’ve washed someone’s hair in the ***** which was quite traumatic, her hair was falling out...” (G, 65-66)</p> <p>“...she continually leaked...and the dignity of the care one of the nurses went up in twos to change the sheets underneath her and the way this nurse just handled this little lump of jelly basically as if she was the most precious thing in world.” (B,248-252)</p>	<p>“...not that hospitals don’t care but that’s not their specialism that’s not what they are geared up for, they don’t have the time, they don’t have the resources, whereas a hospice, that’s their niche” (P, 110-112)</p> <p>“...when I worked in a hospital when a child died it was very much you took them from the ward and you took them to the mortuary and that was pretty much your involvement you had, whereas here it is</p>
	<ul style="list-style-type: none"> Hospice culture and societies perception 		

			<p>very different your very hands on..." (Y,145-148)</p> <p>"...we have the cold rooms which is like a child's bedroom...we have nice little lights in there to make it starrey and em the children can bring in cards and photos and their own bedding." (P,125-127)</p> <p>"We support them with em all the paperwork, order of services, things that they might not of had any experience of doing..." (P, 130-131).</p> <p>"...and it is sad that in our society today death and dying is not talked about because it's the one thing that is guaranteed, you will die one day...people feel so uncomfortable talking about it" (P, 75-78)</p> <p>"...when you say you work in a children's hospice people go ooohhh really and they think its really sad and its not. It's a really happy and wonderful place..." (P, 78-80)</p> <p>"I don't talk much about that with my husband...my husband says oh switch the plug, turn the plug off that sort of conversation..." (B,151-152)</p> <p>"Time, giving families time, we have one-once care...giving families private space, the children have their own bedroom, the sitting room...visitors come...you've got the garden... people who understand the difficult time you are going through to have empathy, to be there to support you and to listen to you, to make sure you get your wishes, the things that are important to you, the memory making..." (P,115-123)</p> <p>"...it does definitely make you think what you would like at the end and what you wouldn't like and how a good death should be..." (Y, 126-127)</p>
		<ul style="list-style-type: none"> Experiences external to hospice 	<p>"...I was about nine and my family are from an Estonian background and it is tradition that you say goodbye to the body, you have an open casket, you go and visit, you kiss." (P, 63 -65)</p> <p>"...I was always very comfortable around dead people...I was used to death and dying being around, I could see the importance of getting it right and how it made you feel...and that someone was still important even though they had passed away..." (P,66-69)</p> <p>"...both my nans were in immense pain...one of them was by themselves...someone had found her in the morning...she died by herself in pain..." (G,120-123)</p> <p>"...I think I was doing an assignment on end of life care, em I was looking after a girl, who was dying in the hospice, my sister had a baby girl at the time em and that because I had a still born baby over twenty years ago brought that all back to me...and that was really difficult." (B,25-30)</p> <p>"...our children here are never by themselves when they die, the family is all around them...if they want to go to Chester Zoo we try and do that for them and make memories...even the ***** just to think you could be in a place like that and not be in a fridge mortuary." (G, 123-126)</p> <p>"People caring as much when you die as they do when you are alive" (G,128)</p>
2	Emotional and behavioural impact	<ul style="list-style-type: none"> Personal 	<p>"Upset, really really upset that it can happen and angry as well for this poor little boy what's happening to him." (G, 37-38)</p> <p>"...the smells, the smells...we used to have a certain air freshener ...and if you ever smelt it out in public you would think uuugghh [cold room name] ...no its not nice." (G, 74-76)</p> <p>"...it was one of the worst we have had to deal with...I think we both felt a little bit traumatised...that was possibly the worst...it was not nice at all..." (Y,44-50)</p>

			<p>“ I think I will always reflect back on it....I don't think that will ever go away...” (Y,74-75) “Upset, really really upset that it can happen..” (G,37)</p> <p>Talking to the deceased child “...still treating them like they were alive, talking to them...” (G, 67) “...I always just try and think they are just asleep and you just talk to them like you normally would.” (Y,39) “...if I had a serious illness and I was palliative I would like to think that I might be able to stay at home...I wouldn't mind if I had to go into a hospice but I'd rather obviously be at home...” (P, 66-102)</p> <p>Choices and options “... you never know when you're going to die or need palliative care...its good to plan beforehand...” (P, 211-212)</p> <p>What you would like/dislike/do/do not want “I think that very much makes you think about what you would like for your own or how what you definitely don't want or what you definitely do want” (Y, 15-16) “It just makes me aware I suppose” (Y, 22) “It definitely make you think about the end and how you, what would be important to you.” (Y, 20) “For me I see palliative care and death and dying as a positive thing not a negative thing and that it is important to think about what is important to you, what your thoughts and feelings are about death and dying...” (P, 209-211) “...I want to be cremated, I don't want a burial site, I want my ashes to be thrown over Moel Famau ...I hate church yards with all the gravestones I think they are a waste of space...you could use up that space for a park for kids to play in...” (P,91-95) “...I tell him about organ donation, I want this going, I don't care what they take, they can have anything they want.” (P,170-171) “...I just really wish that I am treated the way that we treat the children here.” (G, 117-118)</p>
		<ul style="list-style-type: none"> Professional 	<p>Feelings effecting care of the child “... I couldn't go in and do medicines or I'd go in and I would have to face the other way, I couldn't look at him at all...” (G, 25-26) “...when he was first diagnosed with his condition I couldn't look after him, it made me cry, I couldn't go near him...” (G,18-19) “I'm a senior nurse and I felt awful...I'd sit in handover thinking please don't give me that child...” (G,19-20) “...you do feel guilty because sometimes now I don't think twice about going into the ***** I just do it and it doesn't affect me at all but later on you think why doesn't this affect me anymore...there must</p>

			<p>be something...have I been doing it for too long?" (G, 89-92)</p> <p>"In fifteen years he's the first one that ever affected me like that...your meant to be the one that can do anything because you're the senior person" (G, 26, 27,21,22)</p> <p>Realisation of the pressures of the role/ Is this really a nurse's job? Reflection on the role</p> <p>"...I felt as if I shouldn't be feeling like that, I felt guilty that I felt like that because he's another child that should be able to care for, but I couldn't...I should be able to do my job." (G,40-42)</p> <p>"I was doing all three together...that occasion really brought home to me how difficult our job is sometimes and how much we take on as nurses em over and over again." (B, 35-36)</p> <p>"...I do think sometimes here we do have to see too much here, they have been here for so long and I don't know, its just not very nice." (G,56-57)</p> <p>"...who else has to do things like that in their job..." (G, 85-86)</p> <p>"..it is surreal that you could organise a funeral yourself, cos you know what your doing...You feel like you could be an undertaker sometimes because of what you have to do." (G,108,111)</p> <p>"It makes you think how you would do things differently...how you can do your job better..." (Y, 76-77)</p>
5	Coping mechanisms	<ul style="list-style-type: none"> • Metaphors 	<p>"I don't talk much about that with my husband...my husband says oh switch the plug, turn the plug off that sort of conversation..." (B,151-152)</p> <p>"...you put a hat on..." (B, 69)</p> <p>"I think it is definitely self-preservation...it is beneficial to be able to put it away." (Y,207, 210)</p> <p>"You detach yourself a little bit and just pretend that they are still alive...when you are doing things you just chat to them like you usually do, it doesn't seem real really...it's just when you come out you think, oh god have I really done that..." (g, 79-83)</p> <p>"...I am able to switch off I used to go home and get upset and I don't seem to do that as much anymore, I think you switch yourself off..." (G,133-134)</p>
		<ul style="list-style-type: none"> • Hospice support 	<p>Supportive Teams</p> <p>"We have a very strong team...I think that is our main source of support, ...[the team] without a doubt is our main source of support for each other, not what the organisation may or may not provide for us..." (B,41-45)</p> <p>"If I didn't have such a big team and weren't so supportive of each other, the maybe, I would definitely maybe looking for something else for another supportive mechanism or some form of counselling or something like that definitely something to try to help you cope." (Y,245-247)</p> <p>"I have got really good colleagues here as well who I would talk to as well" (G, 290-291)</p> <p>"I don't think I talk about my own personal mortality needs other than say we had a conversation in the office the other day...it was an informal discussion..." (Y, 193-198)</p> <p>That's not what a debrief or 1:1 is for</p> <p>"Usually when we have a debrief it's about that particular child and family and we talk about what went well, what didn't go so well, what you would do differently, how people were thinking and feeling at the time..." (P, 157,159)</p>

			<p>“...I don’t know if that’s the place to do it...” (P, 164) “I have 1:1s with my manager and I don’t think it is something that I would really talk to my manager about...I would choose someone who is more of a friend...I’d be more inclined to speak to be husband about that...” (P, 167-169) “...debriefs at work tend to be what went well and that’s it really...” (B, 277) “...they say 1:1 support is there but nothing formal in the form of supervision...” (B, 272-279) “...I think it’s a place to discuss the death and the care around that...the ones I’ve been to its all been about the child...” (G,156-159) “I suppose there’s some feelings but not really about your feelings, more about feelings for the family.” (G,161-162) “...the debrief doesn’t make me think of my own mortality really I think they make me think of my coping mechanisms but it doesn’t I think make me aware of my own mortality, really just more of my own wellbeing...” (B, 280, 286)</p> <p>Usefulness of debriefs “...it depends on the group that you are with...are they willing to share those kinds of thoughts and feelings?.” (P,155-156) “...it’s a good learning tool...” (P,163) “...it’s helpful to listen to other people’s views and again it’s a good forum to sort of get things of your chest if you felt there was something that needed to be said...” (Y, 163-165) “...it doesn’t bother me talking about death and dying and how I think and feel about it, but I know other people aren’t and I wouldn’t want to put anybody else in a compromising position...” (P,174-176)</p> <p>Provision of a staff counselling service “I think it would be really, really useful for staff to look at their own feelings about how they cope with death of the children...some deaths effect you more than others...I think it would be really useful...” (B, 290-294) “I definitely think it would be beneficial, I think a lot of people would benefit from it...” (Y, 191)</p> <p>Someone impartial to speak to “I think that would be great, I think that would be a fantastic idea...I think to have someone professional who knows what you’re going through and to be accessible. It would be fantastic to have that...” (P,191 -194) “...it’s nice to have someone impartial to bounce ideas off to come to your own solutions...someone to listen to you... I think that would be fab.” (P,198-199) “...its good talking to your friends and family but they have their own thoughts, feelings and opinions ...so to have someone in a counselling role to talk to would be fab...” (P, 204-206)</p>
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		<p>Fear/the unknown “I think some staff would worry that it would open a can of worms...” (G, 173) it was really traumatic...they had never been asked that question, they had never been to consider how they coped with it...people found it really upsetting...we had done it differently it was quite simply because I think because it was a counsellor asking how we were...as opposed to how well we had done...” (B, 230-237)</p> <p>Learn more about yourself/coping mechanisms “I think it would be really, really useful for staff to look at their own feelings about how they cope with death of the children...some deaths effect you more than others...I think it would be really useful...” (B, 290-294) “I definitely think it would be beneficial, I think a lot of people would benefit from it...” (Y, 191)</p> <p>Past experience “...we have tried it before in groups but it didn’t really work then...a counsellor used to come in...you could have one to one sessions...I didn’t get much out of it...she was very counsellory and nodded...” (G, 177-289) “...it was really traumatic...they had never been asked that question, they had never been to consider how they coped with it...people found it really upsetting...we had done it differently it was quite simply because I think because it was a counsellor asking how we were...as opposed to how well we had done...” (B, 230-237)</p> <p>General comments “I think it would probably be good, I think some staff would use it others wouldn’t...” (G, 172) “I have said things that I have never really thought before, but I have not thought that I have thought about it, when you actually sit down and think about it, I think actually maybe it does, you do think about it a lot more than what you actually think you do.” (Y, 194-197)</p>	
	<ul style="list-style-type: none"> Family 		<p>“My husband and children know what I do...they allow me to have quiet time or to talk about things... have some down time... I like gardening, I like walking my dog...” (P,141-142) “I have a very supportive husband...he is probably the main source of support.” (G,189-191) “...you do need stuff outside of work it’s very difficult sometimes to switch off and I think that is an acquired art.” (B,197-198)</p>
	<ul style="list-style-type: none"> Recreational time 		<p>“ I think I was lucky, I think I actually went on holiday a few days after that happened....I think it did me the world of good because I think if I had been here em [I] could well of dwelled on it a lot more than I did.” (Y,80-82) “...I think having those little breaks definitely do help especially if you had a really heavy involvement...” (Y, 91-92) “I’m sure as time goes on that [holiday falling] will change...and that is something that I will just have to learn to deal with I suppose.” (Y, 92-94)</p>

		<ul style="list-style-type: none"> • Self-awareness and boundaries 	<p>“...it’s just dealing with it in your own sort of way.” (Y, 106-107)</p> <p>“...you’ve got to have these boundaries haven’t you to be able to look after yourself...” (B, 75)</p> <p>“...you still need professional boundaries because you need self-preservation as much as anything else.” (B, ?)</p> <p>“... you have got to look after yourself, you have got to move on because inevitably there will be another family coming your way who need your care.” (B, 82)</p> <p>“I suppose it was on my mind a lot more than I think it was...it does stay with you...I’m not going to go home and cry about it...I just think it definitely is something that sticks in your mind....and I’m sure it will for a long time.” (Y, 83-86)</p> <p>“...you can always rationalise things, I suppose that’s how I cope.” (Y,157-158)</p> <p>“I don’t think you realise how demanding it is, you just carry on, it is only when something may happen that it hits you out of the blue and it just strikes you how demanding it can be.” (G,271-273)</p> <p>“You just have to learn to remember that they are not your family...they are nothing to do with you...” (G,94-96)</p> <p>“...there are obviously occasions when you do loose a child here...it does feel like a little bit of a personal loss.” (G,136-138)</p> <p>“I’ve stopped going to funerals as well unless I feel that I need to... I don’t get anything out of doing that now.” (G,139-141)</p> <p>“I have to protect myself now it’s not my loss, you know it’s not my family, I didn’t love that child...I’m older and wiser now...” (G,149-150)</p>
		<ul style="list-style-type: none"> • Remuneration 	<p>“...knowing that I am doing a good job and having the job satisfaction that I have been able to support someone well and that they feel it has been a good experience.” (P,138-139)</p> <p>“...the care that they give you know that makes me very proud to work with them...” (G,252-253)</p> <p>“...I love being able to care for families, sometimes that can be at detriment to yourself...” (Y, 258-259)</p>

APPENDIX 14: Diagram of Overlapping Themes

