

'An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care'

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ABSTRACT

This study examined the experience of clinical staff working in paediatric palliative care (PPC). The involvement of parents in the provision of care alongside professionals and differences in interpreting a child's condition and palliative status by parents, professionals and the children themselves are likely to impact on decision-making and may result in challenges and conflicts of interests. Dilemmas arising from the interplay of potentially opposing perspectives are likely to cause tension and make it difficult for staff to know how to proceed. However, insufficient attention has been paid to understanding staff's experience of these dilemmas. The aims of this study were to explore the dilemmas encountered by staff in PPC. Particular attention was paid to how staff coped and made sense of these dilemmas and whether they drew on any held beliefs, values or other frameworks to facilitate coping or sense making. Actual and desired systems of support which facilitated coping were also explored. The study employed a qualitative methodology. Semi-structured interviews were conducted with nine members of staff and data derived from the interviews was analysed using Interpretative Phenomenological Analysis. Four super-ordinate themes were developed: 'Dilemmas: Familiar Yet Uncomfortable', 'Greater Perspective on Life', 'Moving between the Professional and Personal' and 'Sharing the Burden'. Participants frequently encountered dilemmas in their practice. Building long-term relationships with families provided unique insights into families' lives which participants experienced as enriching through a greater appreciation of their own lives and which helped them to cope. Staff drew on aspects of both their personal and professional identity to help them make sense of dilemmas. They valued a number of support systems including peer support, managerial support and supervision to help them cope and identified ways of achieving greater cohesion. The findings are discussed in relation to the literature and implications for future research and clinical practice were considered.

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TABLE OF CONTENTS

1 INTRODUCTION	1
1.1 Overview.....	1
1.2 Paediatric Palliative Care.....	3
1.2.1 History.....	3
1.2.2 Definition	3
1.2.3 Population	4
1.2.4 Context in the UK	5
1.2.5 Perception.....	6
1.2.6 Differences between Care for Dying Children and Adults	7
1.3 The Experience for Staff	8
1.3.1 The Both And – Rewards and Challenges of Working in PPC	8
1.3.2 Rewards and Meaning-making.....	9
1.3.3 Sources of Stress, Challenges and Dilemmas	10
1.3.4 Coping and Support	15
1.4 Summary and Justification for the Current Research.....	18
1.4.1 A Qualitative Approach to Understanding Dilemmas in PPC	18
1.4.2 Research Questions.....	18
2 METHODOLOGY AND METHOD	20
2.1 Methodology	20
2.1.1 Rationale for Adopting a Qualitative Approach.....	20
2.1.2 Epistemological Position	20
2.1.3 Interpretative Phenomenological Analysis.....	22
2.2 Method.....	26
2.2.1 Procedure.....	26
2.2.2 Research Participants	28
2.2.3 Data Collection.....	29
2.2.4 Transcription and Analysis	31
3 RESULTS	34
3.1 Dilemmas – Familiar Yet Uncomfortable.....	36
3.1.1 Negative Connotations	36
3.1.2 ‘Something’s Stirred up in You’	39
3.1.3 Negotiating Multiple Perspectives	41
3.2 Greater Perspective on Life	43
3.2.1 Being in a Unique Position	43
3.2.2 Knowing What is Important	46

3.2.3	Skewed perspective	49
3.3.	Moving between the Professional and Personal	50
3.3.1	Professional Identity	50
3.3.2	Personal Identity, Values and Beliefs	52
3.3.3	Creating a Distance – Self-care	56
3.3.4	Blurring of Professional and Personal Identity.....	58
3.4	Sharing the Burden.....	60
3.4.1	Creating a Shared Understanding.....	60
3.4.2	The Value of Clinical Supervision.....	64
3.4.3	Space for Connecting with Each Other	66
4	DISCUSSION	68
4.1	Summary of Analysis	68
4.2	Addressing the Research Questions.....	71
4.2.1	What types of dilemmas do clinical staff working in PPC experience?	71
4.2.2	How do staff cope and make sense of these dilemmas? Which held beliefs, values or frameworks do staff draw on in order to help them make sense of the dilemmas encountered in their work?.....	72
4.2.3	What actual or desired systems of support do staff have to help them cope?	77
4.3	Implications and Recommendations	79
4.3.1	Implications for Future Research.....	79
4.3.2	Implications for Clinical Practice.....	81
4.4	Critical Review	83
4.4.1	Quality in Qualitative Research	83
4.4.2	Methodological Considerations	86
4.5	Personal Reflections	88
4.5.1	Reflexivity – Coming Full Circle.....	88
4.5.2	Achieving a Balance.....	88
4.5.3	Final Thoughts	89
5	REFERENCES	90
6	APPENDICES.....	108
	Appendix A: Literature Search Criteria	108
	Appendix B: Registration Document.....	109
	Appendix C: UEL Ethical Approval	110
	Appendix D: Invitation Letter – Children’s Hospice.....	111
	Appendix E: Updated Invitation Letter - Children’s Hospice	113
	Appendix F: Invitation Letter - Community Hospice Service.....	114

Appendix G: Expression of Interest Form.....	117
Appendix H: Participant Information Sheet.....	118
Appendix I: Consent Sheet.....	121
Appendix J: Interview Guide.....	122
Appendix K: Demographic Information Form.....	125
Appendix L: Debriefing Sheet.....	126
Appendix M: Transcription Scheme.....	128
Appendix N: Worked Example of IPA – Participant 2	129
Appendix O: Initial and Cluster Themes – Participant 2	131
Appendix P: Interim Analysis – Themes with Notes	138
Appendix Q: Final Themes	142
Appendix R: Example of an Edited Quote	143
Appendix S: Reflective Journal Extract	144

1 INTRODUCTION

1.1 Overview

The general aim of this study is to explore and articulate how staff working in paediatric palliative care (PPC) experience dilemmas encountered in their work. The study also aims to explore how staff make sense of and cope with the dilemmas encountered, how their belief systems influence the meaning making process and the ways of dealing with these dilemmas and, to understand the actual and desired systems of support which facilitate coping when encountering dilemmas at work.

The study is based on the following assumptions:

- Working with dying children and confronting death and suffering can be both a rewarding and challenging experience for staff working in PPC.
- Clinical staff's experiences are shaped and influenced by an interplay between individual, professional, situational, political and societal factors which provide the context for their practice (see Figure 1 below).
- The involvement of parents in the provision of care alongside professionals and differences in interpreting a child's condition and palliative status by parents, professionals and the children themselves are likely to impact on decision-making and may result in challenges and conflicts of interest (Papadatou, 1997).
- The interplay of potentially opposing perspectives is likely to cause tension and conflict amongst staff and create uncertainty with regards to how to proceed. This notion is encompassed by the term 'dilemma' and will be referred to as such throughout this thesis.
- Clinical staff draw on personal experiences, values, beliefs and other frameworks in order to make sense of the challenges faced at work.
- Clinical staff require support in order to cope with the demands of their work and care for the children and families they encounter in their roles.

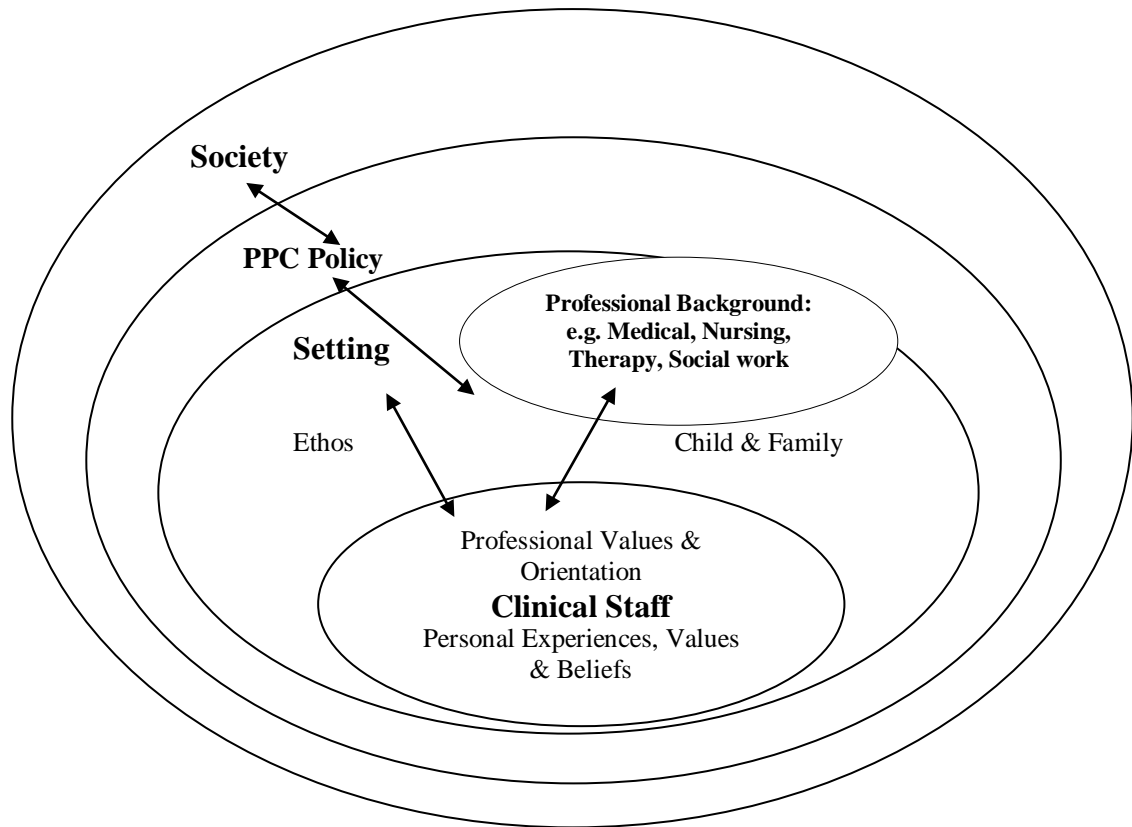


Figure 1: *Interaction between Clinical Staff, Setting and Wider Political and Social Context*

This chapter provides the following:

- an introduction to this thesis, considering the origins of PPC, how it is defined, the population it serves, its perception, emergence and development as a specialty and context in the UK
- a review of the literature¹ covering professional carers' experiences of working with children with life-limiting conditions² and their families
- an outline of gaps in the literature and introduction to the research questions addressed by this study

¹ The literature included in this review was obtained by searching a number of databases as well as other online and printed resources. Appendix A provides an overview of the searches undertaken.

² The term 'life-limiting conditions' is used throughout this study to refer to a wide spectrum of conditions; this is further discussed in section 1.2.3 'Population'.

1.2 Paediatric Palliative Care

1.2.1 History

The concept of palliative care is thought to have derived from the Latin word '*palliate*', which means to 'conceal or alleviate symptoms without curing' (Romesburg, 2007). This focus on comfort and supportive care in contrast to continued aggressive intervention forms the basis of palliative care (Rallison & Moules, 2004). Its roots lie in the hospice philosophy which sought to care for seriously ill and dying patients whose needs were not met in hospitals where the emphasis was on curing patients rather than providing comfort. In 1967, the first hospice was founded in the UK by Dame Cicely Saunders as a place to provide a dignified and comfortable death. However, the need for palliative care services for children was not acknowledged until the 1980s (Cottrell et al., 2011).

The emergence of outreach teams linked to oncology units coincided with the children's hospice movement which aimed to support the needs of children dying from diseases other than cancer, such as metabolic or degenerative diseases (DoH, 2007; Goldman & Heller, 2000). In 1982, the first children's hospice, Helen House in Oxford, opened in the UK (Morgan, 2009; Wheat, 2009). There are now an estimated 44 children's hospices in the country, which are home-like units offering respite to children and families, parent and sibling support as well as bereavement work (CHIMAT & Children's Hospices UK, 2011). However, modern hospice care is a philosophy rather than a facility and spans beyond the actual facility of a hospice to wherever there is a child who suffers from an illness shortening his or her life expectancy, be it in the home, the hospital, residential setting, school or children's hospice (Dominica, 1990).

1.2.2 Definition

Paediatric palliative care (PPC) is defined by the Association for Children with Life-Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health (ACT/RCPCH, 1997) as

'an active and total approach to care embracing physical, emotional and spiritual elements. It focuses on quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement.' (p. 7.)

PPC begins when a child is diagnosed with a 'terminal illness'. It is a common misconception to think of terminally ill children as only those who are in the process of dying. More frequently the term is used to describe both children with life-limiting conditions where premature death is anticipated, as well as those with life-threatening conditions, where premature death is highly likely due to the severity of the illness, but long-term survival to adulthood is possible. PPC continues beyond the diagnostic stage, regardless of whether or not the treatment is directed at the disease (World Health Organization, 1997).

1.2.3 Population

The group of children who are in need of palliative care services in the UK are usually thought of as falling into one of four categories (ACT/RCPCH, 1997; 2003):

- 1) Children with potentially curable conditions such as cancer where curative treatment may fail; palliative care services may be offered alongside attempts at curative treatments.
- 2) Children with conditions which make premature death inevitable, such as cystic fibrosis, muscular dystrophy and human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS); long periods of intensive treatment aimed at prolonging and enhancing life commonly enable children to participate in everyday activities but ultimately these diseases are incurable.
- 3) Children with progressive conditions such as genetic and neurodegenerative disorders where no treatment options are available; treatment is palliative from the point of diagnosis and frequently extends over many years.

- 4) Children with irreversible yet non-progressive conditions with complex healthcare needs, such as severe cerebral palsy or multiple disabilities following brain damage; conditions highly increase children's vulnerability and susceptibility to serious complications and thereby commonly result in premature death.

As can be seen, these children represent a heterogeneous group encompassing a wide spectrum of conditions. The distinction between life-threatening and life-limiting conditions is often arbitrary as in practice, the life-death trajectory is often uncertain and children frequently oscillate between critical illness and the management of chronic conditions before they reach the final stage (Clarke & Quin, 2007).

Therefore, for the purpose of this thesis the following definition by the NHS Executive (1998) will be used to describe any life-limiting condition (LLC):

'Any illness or condition developed in childhood whereby the child is likely to die before adulthood or with a limited expectation of life thereafter. Alternatively, any condition developed in childhood that, without intervention, will cause a child to die prematurely'. (p. 5.)

1.2.4 Context in the UK

As discussed, the population of children and adolescents that benefit from palliative care services is varied due to a broad diagnostic mix. This means that the transition between curative and palliative care is often less clear and varies enormously. Paediatric expertise is often essential in order to adequately care for children with rare and childhood specific disorders (Hynson & Sawyer, 2001). This is further added to by the need of paediatric palliative care services to be both child and family focused in order to fulfill its many objectives.

Traditionally, the growth of services developed over the past twenty-five years in a largely unplanned and ad hoc way, often as a result of both local interest and the availability of charitable funds (Craft & Killen, 2007). Palliative care is

provided through both statutory services, such as health, social care and education, voluntary services and other charitable organizations offering physical, emotional, and spiritual well-being of each child or family, practical help relating to the co-ordination of care, preparation for the future and attempting to maintain a life as normal as possible. In the UK palliative care to children is delivered in a number of ways. This includes children's hospices, family support services, home-based community services and specialist medical and nursing teams. Best practice guidelines (ACT/RCPCH 1997) include care planning, the appointment of a key worker and involvement of a paediatrician, 24-hour support by specialist trained nurses and therapists and the ACT Care Pathway (ACT, 2004) promotes joined-up planning in order to ensure continuity of care and promote partnership working. However, in reality this is not always achieved and that there is great variability across the UK.

1.2.5 Perception

PPC as a holistic approach to care aims to maximise the child and family's potential to appreciate life to the best of their ability. This positive approach is at odds with a dominant view in the Western world that a child's death is shocking and outrageous. In British society, as is the case in many developed countries which reap the rewards of medical advances and health care services, expectations of good health and the curative powers of medicine are high. A child's death therefore opposes society's normative view of children living long and healthy lives (Baum, 1994; Davies & Eng, 1993).

Society's reluctance to contemplate death in children as well as the relatively small number of children with LLCs means that most people will never be confronted with PPC as a field and that it remains a relatively unknown and vague concept. This notion is reflected by two international surveys which found that PPC was unknown to the majority of respondents unless they had been referred to services and that much confusion surrounded the intent and type of services available to children with LLC (Claxton-Oldfield, Claxton-Oldfield & Rishchynski, 2004; Voltz, Akabayashi, Reese, Ohi & Sass, 1997). It appears that PPC as a model of healthcare delivery and emerging specialty is often confused

and even equated with hospice care which produces barriers to the effective delivery of and timing of care for children with LLC (Morstad Boldt, Yusuf & Himmelstein, 2006). Its origins in and emergence from adult hospice care are likely to have contributed to the lack of knowledge and vagueness surrounding PPC. Therefore, the following paragraph will discuss the distinctively different palliative care needs of children compared to those of adults.

1.2.6 Differences between Care for Dying Children and Adults

The diagnosis of a LLC has specific implications for the person concerned, regardless of whether that person is a child or an adult patient. Whilst the experiences of children may parallel those of adults, such as the process of having to come to terms with and adjusting or shared experiences of care deficits, there has been a growing recognition during recent years that the palliative care needs of children are different from those of adults (Clarke et al., 2007; Field & Behrman, 2003). Papadatou (1997) discusses five distinct differences with regards to how the principles of hospice care are applied in clinical practice for adults and children:

- The child's condition and palliative status is likely to be interpreted differently by parents, professionals and the children themselves, which is likely to affect decision-making and may result in conflicts of interest. This is further complicated by ethical and legal issues of self-determination, which are greatly different for children compared to adults.
- Children's needs vary greatly depending on age and developmental level.
- Parents are directly and actively involved in the provision of care alongside health care professionals meeting the children's needs; collaboration between the two may lead to rewarding but also potentially challenging or conflictual experiences.
- The death of a child commonly affects many people and the grieving process is likely to be an intense, long-lasting and complicated one, which is likely to require ongoing support from professionals.

- Professional carers are likely to develop their own unique philosophy on life and death in order to cope with multiple deaths of children and therefore, be uniquely impacted upon by the death of a child.

Papadatou (1997) highlights that the complexity of PPC requires careful consideration and negotiation of multiple often opposing perspectives held by those involved in the care of the child, including those of the whole family and of professionals. PPC is therefore a field which requires specialized skills, maturity and competency and its unique aspects make it a phenomenon which researchers have only recently begun to explore. Whilst it is acknowledged that being confronted by the death of a child and having to care for a terminally ill child will undoubtedly have a profound impact on the family as well as those involved in the care of the child (Matthews et al., 2006), this study focuses on the experience of staff. The following section of this thesis will provide an overview of some of the research conducted in this area. It begins with a discussion of the evidence-base with regards to the experience of staff working in PPC, before pointing to the gaps in the literature and discussing the aims of the present study.

1.3 The Experience for Staff

1.3.1 The Both And – Rewards and Challenges of Working in PPC

The holistic approach of PPC means that the key role of clinical staff in children's palliative is to ensure that all aspects that are important to the child and family, are considered as being central to their care. Illness often results in extreme emotional vulnerability and demands that children and families place their trust in the staff who provide their care. As a result, paediatric palliative care staff frequently encounter families who are 'emotionally shattered' (Maunder, 2006) and their role of caring for the needs of these families can be considered one of the most emotionally challenging areas of nursing (ACT/RCPCH, 2003). On the other hand, however, caring for dying children may be experienced as life-altering, hugely satisfying and rewarding by offering opportunities to create positive experiences and peaceful memories (Clarke et al., 2007; Maunder, 2006). This is reflected in the following quote by Bush Welch (2008):

'It may be painful to accompany a child or sibling on his or her final journey, but the experience has the power to transform lives.' (p. 124.)

1.3.2 Rewards and Meaning-making

The literature provides evidence that clinical staff experience working with children with LLCs and their families as very rewarding (Davies et al., 1996; Papadatou, Martinson & Chung, 2001). According to Rushton (2005; p. 311), the provision of PPC can be 'a source of profound satisfaction, renewal and affirmation'. Working with dying children means that clinical staff are faced with the inevitability of their own mortality which in turn creates opportunities for profound change and personal growth by looking more deeply at their own priorities as well as their own beliefs and values (Powaski, 2006; Maunder, 2006). In Victor Frankl's (1984) 'Man's Search for Meaning', he suggests that meaning in life can be found even in the most hopeless situation, and that when one is no longer able to change a situation, this challenges one to change oneself.

Finding meaning in one's role has been shown to be one way of reducing or neutralizing job-related stressors. Based Maslow's (1970) framework of self-actualization staff find meaning in their work by identifying role-related peak and nadir experiences described as greatly significant, meaningful and unforgettable positive or negative experiences which evoke either a sense of amazement and fulfillment or painful and distressing feelings (as cited by Olson et al, 1998). A qualitative study by Olson et al. (1998) suggested that nurses were able to work with the suffering of families and that of co-workers by reflecting on what was meaningful in their roles and experiencing long-term beneficial consequences. Interviews with 64 paediatric oncology nurses reflected that peak experiences reflected emotional closeness or pleasure which resulted from positive relationships with families and children and a sense that their contribution was positively affecting their care. Beneficial short-and long-term consequences occurred in response to both positive and negative experiences and resulted in changes in values, such as nurses becoming less judgmental; changes in behaviours, such as giving more empathic care; and, changes in perspective, for

example accepting limitations of care. Long-term consequences of peak experiences also showed increased compassion and confidence, an increased comfort in spiritual beliefs and attributing death to both a positive and natural life experience.

A follow-up analysis (Clarke-Steffen, 1998) led to a model of work-related meaning-making. Paediatric oncology nurses appeared to view their work with a sense of fulfillment through a dual process of giving and receiving through interactions with families. The most significant meanings occurred in four main categories: an ability to relate to others, self-awareness, life and death experiences, and, diminishing qualities.

1.3.3 Sources of Stress, Challenges and Dilemmas

Despite the rewards, healthcare workers in paediatric palliative care services are likely to be under considerable stress and anxiety as a result of having to deal with particular difficulties arising from caring for dying children and their families and coming to terms with their own feelings of grief. Menzies Lyth's (1960) seminal study suggested that nurses commonly experience high levels of tension, stress and anxiety brought about by their proximity to suffering and issues of life and death and the arousal of powerful, conflicting feelings and unconscious phantasies. It was argued that in an attempt to create a distance from and reduce nurses' anxiety evoked by human suffering, every attempt was made by the hospital institution to avoid rather than confront their anxiety through the splitting up of the nursing task into impersonal elements. This resulted in job dissatisfaction, high staff turnover and high rates of sickness and absenteeism.

Being unable to save the life of a dying child or eliminate the pain of bereavement is likely to evoke a sense of powerlessness and result in emotional stress. A qualitative study, which addresses the experience of stress by hospice staff working with children identified three main sources of stress: firstly, feelings of impotence as a result of an inability to relieve stress; secondly, having to deal with negative responses in families; and, thirdly, conflicts within the staff team (Woolley, Stein, Forrest & Baum, 1989). Furthermore, expectations of

professionals to manage the emotional impact of their work without allowing it to impact on their work have been shown to be unrealistic. If unnoticed, staff's grief becomes disenfranchised (Doka, 2002) and interferes with the provision of care to children and families (Caine & Ter-Bagdasarian, 2003). Additionally, work related stress is frequently made worse by high workloads and staff shortages (Davies et al., 1996; Papadatou et al., 2001; Maytum, Heiman & Garwick, 2004).

Compassion Fatigue and Burn-out

A qualitative study with PPC nurses revealed that work-related stress was likely to negatively impact on staff's professional and personal lives. Commonly experienced dilemmas relate to balancing work and home life. For example, staff faced with the serious life and death events of the hospice struggle to cut off at the end of the day or tend to view ordinary events in their lives as either trivial or banal (Wooley et al., 1989; McCloskey & Taggart, 2010). Burn-out has been suggested to result from a prolonged process of staff's attempts to cope with the ever increasing demands culminating in the exhaustion of personal resources (Kushnir, Rabin & Azulai, 1997). Multiple deaths during a short timeframe are likely to diminish the capacity to cope and result in burn-out and compassion fatigue (Clarke-Steffen, 1998; Davies et al., 1993; McCloskey et al., 2011; Papadatou et al., 2001; Wooley et al., 1989). Staff feeling physically and mentally exhausted eventually become indifferent, unmotivated and unable to communicate with patients in an attempt to reduce the guilt and frustration associated with stressful work. This is likely to result in staff feeling like a failure both as a professional and a person and may lead to high absenteeism and the decision to leave the profession. The importance of staff support has been raised in order to prevent these highly negative effects of caring for the dying in order to ensure that hospice care does not become dehumanized (Spinetta et al., 2000).

Communication

A staff survey by Contro et al. (2004) indicated that staff members frequently feel inexperienced in communicating with families about end of life issues. This was echoed in interviews and focus groups conducted with PPC staff providing

hospital and community based care in Ireland. Some professionals felt afraid to approach or openly discuss with parents the imminence of their child's death and expressed a degree of collusion (Clarke et al., 2007). Communication difficulties may also arise when staff feel uncertain about how to relate to parents who express their grief through anger or criticism or if they do not share or express their grief (Braun, 2007; Woolley et al., 1989). Staff may resort to distancing tactics to ensure their own emotional survival (Maguire, 1985).

Communication with a child with a LLC has also been shown to be hugely challenging for staff. Whilst open communication about death is a widely accepted recommendation (Hain & Jassal, 2010) and there is a strongly-held belief in Western culture that children should participate in decision-making and be given appropriate information according to cognitive ability, an ethical dilemma related to truth telling has been highlighted in paediatric cancer care. Questions around whether or not to disclose the diagnosis or prognosis to a child may be influenced by cultural or psychological factors and can lead to conflict among the health care team, parents or child (Hatano, Yamada & Fukui, 2011).

A Swedish study using focus group and individual interviews with nursing staff in a paediatric oncology setting revealed obstacles to communication and consequently the development of transcultural caring relationships, especially with families from an immigrant background (Pergert, Ekblad, Enskär & Björk, 2007). In light of the UK's increasingly diverse population the identified obstacles relating to differences in language, culture, religion as well as social and organisational differences are relevant to staff working in PPC in this country.

Team Working and Decision-making

In addition to effective communication, supportive team-working has been found to be vital in helping staff deal with the demands of their work and prevent work-related stress (Barnes, 2001). A study of staff stress and job satisfaction with staff working in a children's hospice found that a threat to the cohesiveness of staff caused by inner staff conflict was a major source of stress (Wooley et al., 1989). Conflicts between staff and parents regarding end-of-life decisions have been

noted in the literature. These give rise to moral distress among staff especially when they have developed a particularly close bond with the child or have concern that the child may suffer as a result of continued life prolonging treatment as opposed to beneficence (Klein, 2009). Similarly, Davies et al. (1996) discussed moral distress in nurses caused by the dilemma of following their obligation to follow treatment orders and their duty to provide a comfortable death. These findings were also supported by Olson et al. (1998) who discussed the dissonance experienced by American health care providers when they perceived institutional pressure to continue actively treating children or when the objectives of care held by the family or team conflicted with the child's needs for palliative care.

A qualitative study of particular relevance for this thesis is that by McCloskey et al. (2011) on the experiences of stress in 18 children's palliative care nurses from hospice and hospital settings in the UK. Focus groups revealed ethical dilemmas related to the withdrawal of treatment, provision of equipment and particularly, withdrawal of feeding. Nurses reported the challenges of trying to reconcile child and parental wishes with conflicting professional and personal beliefs and values and difficulties experienced when advocating on behalf of a child through parents who failed to understand the significance of difficult news or were reluctant to follow professional advice with regards to treatment withdrawal. The study highlighted better coping with these dilemmas by the specialist hospital nurses compared to the hospice and community nurses. It was suggested that nurses who had previously experienced similar situations were able to manage the uncertainty evoked by the dilemmas through reflection, testing of ideas and refined coping strategies.

Another challenge is the prognostic uncertainty that surrounds most LLCs which may lead staff and families to cling onto hope that a child might survive when this may not be realistic. This makes decisions to switch from curative to palliative approaches to care extremely difficult and distressing. De Graves and Aranda (2005) conducted an exploratory study with nurses, doctors and social workers working on haematology/oncology unit and found that decision-making was not experienced as a discrete entity but gradually developed through a slowly

developing awareness and acceptance by staff and families that a cure was no longer achievable goal (De Graves et al., 2005).

A study of particular relevance to this study involved focus groups with PPC staff in Ireland (Clark et al., 2007) which highlighted the complexity of informed and inclusive decision-making between those caring for children with LLC and their families. Staff accounts illustrated that their engagement with families exceeded the medical realm and was instead characterized by close relationships with children and their parents and connectedness with the family beyond a child's death. This helped to facilitate an environment where cure was no longer the focus of care but care was about helping to normalize the given circumstances and helping to manage the uncertainty surrounding the arrival of the terminal phase. Managing uncertainty seemed key in taking on board parental judgements with regards to doing the 'right thing' and in facilitating collaboration with parents in decision-making. This highlights that the relationship between staff and parents is of vital importance when caring for children with LLCs. However, challenges to staff-family relationship occurred when the reality of the inevitability of the child's death was denied as a result of collusive engagement between staff and parent or parent and child.

Emotional Impact - Grief Responses and Process

Clinical staff accompany children through the dying process and frequently witness the death of a child. The emotional impact of this has been explored by several researchers who identified a variety of grieving responses (Davies et al, 1996; Papadatou, Bellali, Papazoglou & Petraki, 2002; Papadatou et al., 2001). In practice, however, the expression of grief is frequently interpreted as a sign of vulnerability and therefore, strongly discouraged by institutional regulations. This is further entrenched by society's expectation of professionals to remain strong and indifferent when confronted by death and as a result grieving is often kept hidden and disenfranchised (Liben, Papadatou & Wolfe, 2008). Disenfranchised grief means that people cannot publicly mourn because the importance of the loss of their relationship is not socially recognized. When relating this to PPC

staff, this means that they cannot publicly express their grief and mourn and as a result are deprived of social support.

Davies et al. (1996) interviewed 25 nurses and found that grief distress is a commonly experienced dilemma, a finding of particular relevance to this thesis. Nurses commonly felt that expressing their sadness conflicted with what was expected of them professionally and it appeared that grief distress was compounded in environments which failed to acknowledge the profound effect for paediatric palliative care for nurses. Papadatou et al. (2001) discuss the unique characteristics of mourning as a dual process (Stroebe & Schut, 1999). This means that caregivers constantly shift between an exploration of their grief as a means of meaning making and avoidance or repression of their grief in order to cope and adjust. This healthy and adaptive process enables clinical staff to attribute meaning to both the death of a child and their contribution to the child and family's care. Meaning making of the experience of death has been highlighted as the central aspect of the grieving process (Neimeyer, 2001). A qualitative study interviewed 16 Greek oncologists and 14 cancer nurses to explain and make sense of the deaths they encountered. Whilst this was a difficult task for nurses due to their perception of death as unfair, some nurses drew on their beliefs to explain and make sense of their experiences suggesting that death was either: the consequence of a fatal disease; the result of fate, pure chance or part of a life cycle; the result of a higher force; or, that it could not be understood and had no meaning at all. Whilst nurses readily attributed meaning to their contribution to the care of the dying child, oncologists more readily gave biological or scientific explanations (Papadatou et al., 2002).

1.3.4 Coping and Support

The previously discussed challenges and demands faced by staff working in PPC settings point to the importance of beneficial coping strategies and support systems to prevent burn-out. A variety of coping strategies have been described in the literature. These include personal ones that have been found to be effective in the short term, such as self-care activities or journal writing, and long-term ones, such as a personal philosophy of care, and ability to be reflective and

self-aware as well as a commitment to care for oneself. Work-related coping strategies include the development of supportive professional relationships (Maytum et al., 2004). It appears that health professionals in PPC not only rely more on their colleagues for support as opposed to friends and relatives but that the nature of the support differs, providing informational, clinical, emotional and meaning-making support (Papadatou, Papazoglou, Petraki & Bellali, 1999).

Informal support from colleagues, especially other nurses, seemed to be one of the most important factors in helping staff cope with the demands of their work. When nurses were able to acknowledge or express their distress through sharing the struggle they appeared to be more able to resolve their distress and apply their acquired experience and knowledge when working with other children. However, not all nurses were able to seek support because of beliefs relating to professional conduct, which expected them to control their emotions, or a perception that colleagues were too busy to seek support (Davies et al., 1996). Bereavement debriefing sessions have also been found to be a helpful and effective approach to supporting health professionals with their grief in caring for children with life-limiting conditions (Keene, Hutton, Hall & Rushton, 2010) although they are not routinely offered in paediatric palliative care services.

It is, however, not only coping strategies and support systems that ease work pressures and stress. According to Benner's (1984) conceptual model of nursing, experiential learning enables nurses to cope with the emotional, physical, psychosocial and social demands of their work. Working in a setting for a long time helps nurses not only to consolidate and build knowledge but also to gain expertise. Therefore, nurses learn from experience and develop strategies that help them cope with the demands of their role as they become more exposed to the challenges in their work.

It has also been suggested that professionals working in an area of high emotion work, that is the work involved in managing feelings in both oneself and others (Hochschild, 1983), develop protective strategies. For instance a shared and underlying philosophy of care or 'dark humour' becomes a means of nurses to protect themselves against the emotion work of their role. They are likely to share

an emotional response that is expected of them in their role, so-called surface acting, whilst keeping their private emotions hidden. Managing emotion work in PPC and the knowledge base for best practice when caring for children with LLCs requires considerable expertise which sadly is often underestimated (Maunder, 2006).

Caring for dying children poses emotional and psychological challenges for staff and may bring them into contact with their underlying fears and beliefs resulting in powerful feelings, such as anxiety, loss or conflict. The distress of palliative care staff is likely to be unconsciously expressed in their practices unless there is sufficient space to unearth and address this distress with the help of an external facilitator (Hinshelwood & Skogstad, 2000). The importance of training and good support systems to educate staff in understanding human responses to grief and prevent them from resorting to distancing tactics or distress, have been discussed by Wooley et al. (1989).

The provision of support groups as a means for shared goal setting and decision making as well as reflection and evaluation of the care provided has been noted in the literature (Barnes, 2001). Whilst groups were sometimes perceived as painful they were nevertheless valued and showed good attendance in one study (Wooley et al., 1989). Benefits of support groups were particularly evident if facilitated by an experienced group work facilitator and conducive to discussing work related difficulties (Spinetta et al., 2000). Clinical psychologists benefit from a training which provides them with detailed knowledge and insights of human development across the lifespan, cognitive functioning, personality development as well as group dynamics and they therefore bring a unique perspective. With their broad and deep knowledge and skills base, clinical psychologists are well placed to support staff in recognizing signs of stress and burn-out and promoting good self-care through consultation, staff supervision and reflective practice (Kalus, et al., 2008).

1.4 Summary and Justification for the Current Research

1.4.1 A Qualitative Approach to Understanding Dilemmas in PPC

When a child is diagnosed with a LLC it is likely to impact on the wider family system. This is reflected in the PPC approach which is a holistic one taking into account both the needs of the child and the family (ACT/RCPCH, 2003). In fact, it has been argued that the needs of every family member are of equal importance to the needs of the ill child (Deeley, Stallard, Lewis & Lenton, 1998). However, this makes the provision of adequate care for children with LLCs a complex undertaking which requires involvement and consideration of everyone involved as well as careful negotiation of multiple often opposing perspectives. Despite best efforts this is likely to result in challenges, conflicts and dilemmas which will affect the whole system. Whilst there is a limited evidence base that suggests that PPC staff encounter challenges and dilemmas in their work, little is known about the ways in which staff experience, cope and make sense of these dilemmas. There also appears to be a lack of research which addresses in how far staff's values and belief systems influence the meaning-making process of and ways of dealing with dilemmas. Although the literature illustrates that the loss of a child can have a significant impact on staff on a number of levels (Papadatou, 2000), the evidence base highlights a lack of opportunities for staff to process their personal and professional responses and make meaning of a patient's death (McCoyd & Walter, 2007). Therefore this study also hopes to explore staff's actual or desired systems of support which help staff to cope with the demands of their work.

1.4.2 Research Questions

In light of the existing research and identified gaps in the literature, this study hopes to contribute to the value of clinical psychology within PPC and aims to address the following research questions:

- What types of dilemmas do clinical staff working in children's hospices experience?

- How do staff cope and make sense of these dilemmas?
- Do staff draw on any held beliefs, values or other frameworks in order to make sense and deal with these dilemmas?
- What actual or desired systems of support facilitate coping?

2 METHODOLOGY AND METHOD

This chapter discusses the study's methodology, i.e. the general approach to researching the topic in hand and the method used, i.e. the specific technique applied to this study (Silverman, 1993). The first part of this chapter focuses on the methodology by outlining the following: the rationale for adopting a qualitative approach; the researcher's epistemological position; and, interpretative phenomenological analysis (IPA) as a chosen methodology. The latter part of this chapter focuses on the method employed: the design; how research participants were recruited and selected; the way in which interviews were conducted; and, how the data was transcribed and analysed.

2.1 Methodology

2.1.1 Rationale for Adopting a Qualitative Approach

Qualitative research is concerned with meaning; it aims to understand how people experience and make sense of the world. Whilst it is 'the objective of qualitative methods [is] to describe and possibly explain events and experiences' (Willig, 2008, p. 9), this contrasts with the objective nature of quantitative research, which is concerned with identifying cause and effect relationships and predicting outcomes. It is argued that approaching the research topic quantitatively would have imposed meaning through pre-defined variables and the testing of hypotheses, and therefore, prevented research participants from identifying their own ways of making sense of their experiences. Given that the study aims to develop new understandings of the dilemmas encountered by PPC staff and is concerned with the meaning attributed by staff to their experiences, then an exploratory approach is indicated (Willig, 2008).

2.1.2 Epistemological Position

Qualitative research encompasses a variety of methodologies. Whilst they are united by a shared characteristic of describing 'experiences, behaviours, interactions and social context without the use of statistical procedures or

quantification' (Fossey, Harvey, McDermott & Davidson, 2002, p. 717), they vary with regards to the methods employed and the assumptions held by the researcher (Harper, 2008).

Interrelated questions of ontology (what is there to know?), epistemology (how and what can we know?), methodology (what general approach do we take to gaining knowledge about the world) and methods (how are data collected?) shape the framework of beliefs and assumptions that guide research (Denzin & Lincoln, 2005). As a researcher's epistemological position determines the researcher's assumptions held about the relationship between the data and the world (Harper, 2012), clarity regarding one's epistemological position is essential. This ensures consistency between the methodology and method employed and a study's claim to knowledge which is implicit in the research question (Willig, 2001).

Qualitative research can be differentiated by the extent to which the data is seen to be a reflection of reality. Within this dimension qualitative methods lie on a continuum; at one end lies realism, with relativism placed at the opposite end. Realism assumes the existence of a true reality which is mirrored in the collected data and uncoverable by the researcher. Relativism, on the other hand, denies the existence of an observable truth or reality that exists separately from our constructions of events; observations can be interpreted in many different and valid ways and collected data is therefore, not considered to be a reflection of reality (Harper, 2012). Between these two opposing poles lie methods that adopt a critical realist position.

This research assumes a critical realist stance in that it assumes the existence of real entities. However, these can only be partially apprehended (Nightingale & Cromby, 1999). The approach assumes that people's embodied experience is meaningful and reflected in the use of their language but that the researcher's understanding of experience is essentially constructed and therefore tentative.

This research also assumes a contextual constructionist position (Jaeger & Rosnow, 1988) in that it argues that the study's findings will depend on the

context of data collection and analysis. As identified by Pidgeon and Henwood (1997, p. 250) knowledge production is affected by four dimensions: (1) participants' own understandings, (2) researchers' interpretations, (3) cultural meaning systems which inform both participants' and researchers' interpretations, and (4) acts of judging particular interpretations as valid by scientific communities'.

2.1.3 Interpretative Phenomenological Analysis

According to Smith, Flowers and Larkin (2009), IPA is

'[...] concerned with the detailed examination of human lived experience, and it aims to conduct this examination in a way which as far as possible enables the experience to be expressed in its own terms, rather than according to predefined systems' (p. 32).

IPA draws on the traditions of phenomenology, as it is concerned with people's perceptions of the world, and hermeneutics, as it recognizes the researcher's central role in making sense of the participants' experiences (Smith, 2004). Whilst IPA attempts to produce an account, which is as close to the participants' views as is possible, it also acknowledges that the account produced by the analytic process is not a genuinely first person account but one that is co-constructed by both participant and researcher (Larkin, Watts & Clifton, 2006). IPA therefore, recognizes that data analysis involves a process of interpretation by the researcher through their engagement with the data. According to Smith and Osbourne (2003), IPA involves a 'double hermeneutics' whereby the participants attempt to make sense of their social and personal world and the researcher then tries to make sense of the participants' sense making process. Flexibility within the approach permits a rather critical reading of participants' accounts of their experiences, and therefore allows for the analysis to draw on both an empathic and a questioning hermeneutic (Smith, 2004).

Why is IPA Appropriate to this Study?

The aims of this study are to explore and articulate the experiences of staff working in PPC with a particular emphasis on the dilemmas they encounter in their work, the ways they make sense of these and their perceptions of the support they receive.

The application of IPA is deemed an appropriate method for this study for a number of reasons:

- 1) it offers an explanatory account suitable for an under-researched area;
- 2) its objective of describing and possibly explaining how people make sense of their experiences is consistent with this study; and,
- 3) its idiographic approach is most relevant to this study as it attends to a population that lacks opportunities to articulate their viewpoint in research.

Semi-structured Interviews

IPA advocates for a data collection method which provides opportunities for participants to share their experiences through first-hand accounts. One such method, which facilitates access to rich and detailed accounts and elicits 'stories, thoughts and feelings about the target phenomenon' (Smith et al., 2009, p. 56), is that of semi-structured interviews. Semi-structured interviews allow the interviewer to be responsive to any concerns shared by the interviewee and be flexible to explore and follow up on matters arising in the context of a particular interview in an unprompted way (Smith & Osborn, 2003). However, this way of collecting data can never be neutral (Rapley, 2001).

Using an interview schedule seemed suitable for this study as it allowed me, as the interviewer, to loosely decide on topics I wanted to discuss with participants, to prepare for and be explicit about potentially sensitive issues arising during the interview and to frame questions in a suitably open form. The non-prescriptive nature of the schedule enabled me to concentrate on engaging with participants and create an interaction in which both I and the interviewee were actively engaged. This collaborative approach provided sufficient structure and prompts to support the expression of participants' views whilst emphasizing the

interviewee's role as 'primary expert' (Alexander & Clarke, 2004, p. 82). In my opinion, this proved to be a helpful approach to collecting good quality data.

The Position of the Researcher

In keeping with IPA's objective of understanding the world of research participants, this study focused its attention on clinical staff's experiences of dilemmas in their line of work. However, it is vital to acknowledge that the process of exploring and arriving at an account of experience is always partial and multifaceted (Smith, 1996) as a result of being co-constructed by the participant and researcher (Larkin et al., 2006). All aspects of a research study will therefore be influenced by the personal and professional identities held by the researcher. It is therefore essential for researchers to own and make explicit their positions and specify their initial and emerging anticipations. By recognizing their assumptions and values, researchers enable readers to understand and evaluate the research and consider possible alternatives (Elliott, Fischer & Rennie, 1999). Whilst this will be discussed in greater depth in 'Chapter 4', I will now introduce some of the positions and identities I hold which are likely to have influenced my approach to conducting this study. I identify myself as a white, woman in my early thirties and a Trainee Clinical Psychologist. Whilst I am not a parent and therefore have limited experience of children on a personal level, I have substantial experience of working with children and adolescents in a professional capacity, both prior to starting and whilst on clinical training.

Most important for this thesis, has been my experience of working with children and adolescents with severe learning disabilities and complex, often multiple physical health needs. Whilst the children and families I worked with accessed support through a specialist learning disability service, many were identified as having conditions that reduced their life expectancy and would have fulfilled criteria for PPC services. I believe that my professional experience of working with this client group enabled me to approach the lived experience of my participants with empathy, curiosity and an appreciation for their roles; however, I am also aware that my professional status may have created demand characteristics (power imbalance, expectations etc.) that are typical of conversations or joint-working with professionals from multiple professional

backgrounds. I have attempted to address these by taking a number of steps which are discussed in section 2.2.3, under *'Interview Procedure'*.

Although I consider my experience of children with LLCs more professional than personal as I do not have any children of my own, I am aware that my childhood memories of Julia, my best friend during my primary school years have been influential. Julia had Duchenne muscular dystrophy, an incurable condition causing muscle weakness and progressive difficulties with walking and leading to disability and eventually to premature death. Despite my relatively young age, my parents had been very frank with me about Julia's condition and openly discussed the prospect of a premature death. Having attended a number of funerals as a young girl, I grew up accepting death as a fact of life and believing in life after death which was informed by my Catholic upbringing. Perhaps this reflected in my friendship with Julia; despite my awareness of the implication and prognosis of her illness, we never allowed her condition to define us or stand in the way of our friendship. This made me aware of the reality of living with a LLC and the impact this can have on the whole family; at the same time, I witnessed my friend's unfaltering bravery, strengths and positive outlook on life. Although we were no longer in contact by the time I learned that Julia had died aged 29 years of age, my experiences and memories of that time have stayed with me. As a result, I am inclined towards approaching illness and disability as something that is secondary to rather than defines a person and although I am no longer a practicing Catholic, I do continue to accept and approach death as a fact of life.

Another key experience which influenced the focus of my research was that of working in an acute inpatient setting many years ago. Being part of the nursing team, I was confronted with the difficulties faced by unqualified and nursing staff such as the felt power imbalance compared to other members of the multi-disciplinary team and the fast pace and relative isolation resulting from working in a busy ward environment. I also felt first-hand how the demands of the work impacted on staff and created stress and tension which reflected in the dynamics of the team and ward atmosphere. Experiences often felt too painful to acknowledge or discuss thus hindering staff's capacity to think. This struggle was particularly evident in staff support groups which were frequently cancelled and

generally had a low attendance as well as the minimal provision of supervision. This was a valuable learning opportunity for me personally and professionally as it led me not only to recognise the importance of staff support and opportunities for reflection in busy working environments but also to appreciate the role that clinical psychologists can play in providing such opportunities to staff.

Although IPA acknowledges that any phenomenon under investigation will inevitably be influenced by the researcher's preconceived values, assumptions and expectations, the aim of the researcher is 'to reveal any subject-matter on its own terms' before making an attempt to interpret what the particular experience means for a participant within his or her context (Larkin et al., 2006, p.108). I attempted to recognize and suspend any preconceived beliefs I hold by keeping a reflective journal throughout the research process. This will be discussed in greater detail section 4.6.2.

2.2 Method

2.2.1 Procedure

Registration and Ethics

Prior to approaching potential research sites and starting recruitment, the research study was registered with the University of East London's Research Degrees Subcommittee on behalf of the University Quality and Standards Committee (Appendix B). Ethical approval was obtained from the Ethics Committee of the School of Psychology, University of East London (Appendix C).

Services

Prior to starting recruitment, the researcher consulted with a clinical psychologist who works in an NHS community paediatric palliative care team in London on service needs, gaps in the literature and feasibility of recruitment. Whilst the NHS service was deemed unsuitable as a research site due to service pressures and small staff numbers, a number of other potential settings for recruiting participants were identified, all of which were charitable foundations.

The research took place in two settings: a children's hospice in London; and, a hospice at home service in greater London. The study's research supervisor had previously worked at the hospice and liaised with the team manager around the service's potential involvement in this study. Following this, the researcher met with the team manager and was given permission to recruit staff from the hospice. Contact with the hospice at home service was established by the researcher directly through email and phone contact with the team manager, who subsequently invited the researcher to present the study proposal at a multi-disciplinary team meeting.

Recruitment

Email invitations to participate in the research study were disseminated to hospice staff by the team manager (Appendix D). Due to an initial low response rate, this was followed up by a further email invitation sent to all clinical staff by the team manager (Appendix E). The second mail shot included testimonials written by hospice staff who had already taken part in the study; this, as well as word of mouth encouraged other staff members to contact the researcher and express an interest to participate.

Staff members from the hospice at home service were recruited after I presented my proposal during a team meeting. Prospective participants were given invitation letters (Appendix F) and had an opportunity to ask questions. They were asked to indicate their interest in participation by completing a 'Expression of Interest Form' (Appendix G) handed around after the presentation.

The researcher contacted prospective participants from both settings via phone or email to further discuss the study, offer an opportunity to ask questions and arrange a time and place to meet for an interview. Staff were given a choice of being interviewed at their place of work or any other suitable location. This was considered beneficial in enabling participants to feel a sense of control and confidence and establishing rapport (Woods, 1986). Prospective participants were then emailed a 'Participant Information Sheet' (Appendix H) and 'Consent Sheet' (Appendix I). They were also given printed copies of the same documents at the interview.

2.2.2 Research Participants

Sampling

Qualitative research is field orientated in nature and therefore requires purposive sampling, which is consistent with IPA's orientation. Participants for this study were therefore selected according to predetermined criteria and the sample was homogenous to the extent that participants were able to share their particular perspectives on the phenomenon under investigation (Smith et al., 2009).

The size of a sample is commonly established inductively until 'saturation' has been achieved, that is when there are no further observable themes in the data (Guest, Bunce & Johnson, 2006, p. 59). However, research protocols frequently require researchers to pre-determine the number of participants, thus making data saturation an impossible determinant of sample size. This study's sample size of 8-12 participants was set in accordance with evidence-based recommendations by Guest et al. (2006) which suggest that twelve interviews commonly produce data saturation. It also took into account guidelines by Smith et al. (2009, p. 51) who proposed that 'IPA studies usually benefit from a concentrated focus on a small number of cases' and emphasized the importance of quality rather than quantity given that IPA concerns itself with describing individual experience in detail.

Inclusion/Exclusion Criteria

The main inclusion criterion was that participants were clinical members of staff in a paediatric palliative care setting. Clinical staff was defined as a member of staff whose primary role included close contact, support and care of children with LLCs and/or their families; this included unqualified care staff such as support workers or nursing assistants as they have been shown to play an important role in PPC (Swinney, Yin, Lee, Rubin & Anderson, 2007). Participants were required to be aged 18 years and above to simplify consent procedures and to have worked in the palliative care setting for a minimum of three months to ensure they were sufficiently familiar with the service context.

Participants

A total of eighteen members of staff initially expressed an interest in taking part in this study. Four out of six interested hospice staff attended interviews as agreed. Out of the twelve members of staff working at the hospice at home service, six staff agreed to meet for interviews; five attended as planned whilst one person was unable to attend due to an emergency at work. The remaining six members of staff were either not contactable or had insufficient time to meet for an interview.

The nine interviewees came from a number of professional backgrounds, including nursing, youth work and counselling. The sample included two men and seven women. Their ages ranged between 32 and 55 years of age. Six of the participants described themselves as 'White British', two as 'White Irish' and one as 'Mixed British South Asian'. In terms of religion, two staff described themselves as 'Christian', two as 'Catholic' with one as not practicing, one each as 'Church of England', 'Protestant' and 'Buddhist' and two as 'None'. The length of time spent working in PPC ranged from two years to 25 years. Six of the participants had no children, whilst three staff had two children each (Appendix J).

2.2.3 Data Collection

Interview Schedule

The interview guide (Appendix K) was developed in line with the following suggestions made by Smith et al. (2003):

- 1) Three main topics relating to the aims of the study were identified; these included experiences of dilemmas in the work of PPC staff; sense making and coping; and, staff's experience of support.
- 2) Topics were sequenced in order to both create a coherent order and to gradually work towards more specific areas by focusing on 'scene setting' (Smith et al., 2009, p. 61) topics at the beginning to allow participants to settle into the process and feel more relaxed and comfortable.

- 3) The interview schedule included many open-ended questions that were aimed to be neutral and avoided jargon as well as prompts and probes that allowed the researcher to follow up on responses to the main question therefore allowing more specific exploration of the theme in question; the aim was to be as non-directive as possible whilst taking into account variation in participants' communication styles and engagement in spontaneous communication.
- 4) The preliminary schedule was shown to the research supervisor and adapted based on suggestions made about the number of questions asked and the wording of specific questions and prompts.
- 5) Semi-structured interviews allow for the modification of initial questions in light of participants' responses. A staff member from the children's hospice whose role was not primarily clinical in nature consented to a pilot interview. Whilst the process of the pilot interview informed the research process by enabling me to test the questions and make minor amendments to the schedule, the data was not included for analysis.

Interview Procedure

Smith's (1995) guidelines for good practice in conducting interviews were followed by the researcher. Prior to the beginning of the interview, I explained the purpose of the interview, confidentiality and its limits, and participants' right to withdraw from the study at any time during or after the interview, without the need to state a reason for their decision. I then asked participants to read the information sheet (Appendix H) and complete a consent form (Appendix I) of which they were given copies to keep. Participants were also asked to provide basic demographic information (Table 1, chapter 3). All interviews were conducted in meeting or clinical rooms at either service setting; rooms had been pre-booked by me and provided a private space for interviews to take place without interruptions or anyone else present. The participant and I sat at opposite ends of a small table on which the digital voice recorder was placed. The recorder was only switched on once the participant had been able to ask questions and was ready to commence the interview.

I am aware that the formality of the work setting may have constrained participants' responses, however, this was balanced against the time pressures placed on staff as well as issues with regards to finding an alternative setting which allowed easy access for participants and provided a confidential and safe space. In order to maximize participants' engagement I used the following strategies to conduct interviews. I explicitly framed the interview as a conversation which allowed participants to share what felt important to them rather than feeling pressure to give 'right' or 'wrong' answers. I encouraged participants to ask questions and seek clarification throughout the interview if necessary and gave them permission to 'opt out' of questions if they felt uncomfortable. I also explained to participants the 'pause' function of the recorder, therefore allowing them to take a break from the interview if required or to say something 'off the record' if appropriate.

Once the interview was complete and recording terminated, participants were invited to comment on their experience of taking part in the interview and share any additional comments they might have had. I then gave participants a debriefing sheet (Appendix L) which clarified the rationale of the study and contained both my contact details as well as those of two confidential help lines which participants could contact in the event they wanted to discuss any issues. Interviews varied in length, ranging from 55 minutes to 90 minutes with the average interview lasting approximately one hour.

2.2.4 Transcription and Analysis

Data Preparation

As discussed in section 4.6.2, I reflected on the interaction by making notes in my reflective journal after each interview. These included thoughts and observations of the process, particularly whether my assumptions had led me to attend more to certain aspects of the interview than others and whether these had been reflected in interviewees' responses. I also endeavoured to transcribe each interview as soon as possible after it had been conducted to ensure I was still sufficiently familiar with the interaction and content. I adapted my transcription conventions

(Appendix M) from those provided by Potter and Wetherell (1987) and Silverman (2002). I transcribed audio recordings verbatim and at a semantic level which included pauses, laughs, emphases, repetitions and interruptions. I then added line numbers and anonymised transcripts by inserting pseudonyms and removing any identifying information.

Procedure for Data Analysis Using IPA

When analysing the interview transcripts, I broadly followed the stages suggested by Smith et al. (2003; 2009) whilst also trying to find my own way of working by making adaptations as required; these stages are discussed below. Initially, I analysed transcripts individually before integrating themes across transcripts thus maintain idiographic approach.

- 1) The process began with familiarising myself with one transcript by reading it several times. I noted anything of interest in the right-hand margin by commenting on the language used or associations made. The entire transcript was treated as data and no rules were imposed on what could be commented on.
- 2) Upon re-reading, I transformed my initial notes into initial themes³ which I noted down in the left-hand margin of the transcript. By making links with psychological theory, I was able to move to a slightly higher level of abstraction whilst remaining closely connected to what participants had actually shared. For an example of a worked transcript, see Appendix N.
- 3) After I composed a list of the initial themes, I then attempted to make connections between the initial themes by developing cluster themes which were ordered coherently and labelled and included line number references (Appendix O). This process was iterative and required me to constantly check that my interpretations and the connections made

³ I chose the term 'initial themes' to reflect that themes developed as a result of my engagement with participants' accounts; this contrasts the frequently used term of 'emergent' theme which carries a naive realist connotation and is inconsistent with the epistemological position of this study.

between themes continued to reflect what participants had originally said and that this fitted within the context of the interview.

- 4) I then repeated stages one to three for the next five transcripts which led to the development of further lists of initial and corresponding cluster themes. When analysing the transcripts I attended to both divergence and convergence across participants' accounts. The additional lists of themes were then integrated to develop a set of super ordinate themes with accompanying notes to describe their possible meanings. This constituted the interim analysis (Appendix P).
- 5) The final three transcripts were then analysed by following the above steps. Whilst I compared the developing themes against those from the interim analysis I remained open to new themes.
- 6) Once all transcripts had been analysed I developed a consolidated list of super- and sub-ordinate themes (Appendix Q). This process of consolidation required me to reduce the data by prioritising certain themes over others. Decisions were not only made based upon how consistent themes were represented in the accounts but also on the richness of the data that supported these themes.

3 RESULTS

This chapter presents the findings of the analysis carried out on the transcripts obtained from interviews with the nine research participants. Table 1 overleaf ('Demographic Details of Participants') presents essential demographic information gathered from each participant.

Table 2 below provides an overview of the super-ordinate and corresponding sub-ordinate themes; these are discussed in detail in the succeeding sections of this chapter. It is worth noting that themes are not regarded as discrete entities but should be read as being inter-related.

Table 2: *Super-Ordinate Themes and Corresponding Sub-Ordinate Themes*

SUPER-ORDINATE THEMES	SUB-ORDINATE THEMES
Dilemmas: Familiar Yet Uncomfortable	<ul style="list-style-type: none">• Negative Connotations• 'Something's Stirred Up in You'• Negotiating Multiple Perspectives
Greater Perspective on Life	<ul style="list-style-type: none">• Being in a Unique Position• Knowing What is Important• 'Skewed Perspective'
Moving between the Professional and Personal	<ul style="list-style-type: none">• Professional Identity• Personal Identity, Values and Beliefs• Creating a Distance – Self-care• Blurring of Professional and Personal Identity
Sharing the Burden	<ul style="list-style-type: none">• Creating a Shared Understanding• The Value of Clinical Supervision• Space for Connecting with Each Other

Table 1: *Demographic Details of Participants*

Participant⁴	Job Title	Gender (M/F)	Age	Setting	Ethnicity	Religion	Years Worked in PCC	Children? How many?
P2: Sarah	Senior Nurse Specialist	Female	32	Children's Hospice	White Irish	Catholic (not practicing)	2	None
P3: Anna	Family Support Services Manager	Female	55	Children's Hospice	Mixed British South East Asian	Buddhist	6	None
P4: Tim	Nurse Specialist/ Transition Lead	Male	32	Children's Hospice	White British	None	9	None
P5: Katie	Nurse Specialist	Female	52	Community Hospice Service	White British	Christian	6	2
P6: Sue	Nurse Specialist	Female	45	Community Hospice Service	White British	Christian	9	None
P7: Paula	Nurse Specialist	Female	52	Community Hospice Service	White British	Church of England	3	2
P8: Claire	Nurse Specialist	Female	45	Community Hospice Service	White British	Protestant	12	None
P9: Jenny	Youth Worker	Female	48	Community Hospice Service	White British	Catholic	3	2
P10: David	Nurse Consultant/ Interim Care Manager	Male	53	Children's Hospice	White Irish	None	25	None

⁴ Pseudonyms are used to preserve participant anonymity

3.1 Dilemmas – Familiar Yet Uncomfortable

This theme conveys the participants' accounts of their familiarity with dilemmas in their daily working lives. The term 'dilemma' was suggested to carry a negative connotation and staff suggested that dilemmas made them feel uncomfortable and challenged them both as individuals and professionals.

3.1.1 Negative Connotations

Participant accounts suggest that staff were familiar with the concept of dilemmas and that these occurred almost on a daily basis thus forming an intrinsic part of participants' working lives.

⁵[...] it's being in a situation where you've got choices to make. (I: Mmh.) [but] you've struggled to work out which is the best way to go for [pause] myself, for the family, for the child. [...] that's almost around on a daily basis, [...] with this job (I: Mmh.) yeah. (Katie, 341-351⁶.)

Katie suggests that being confronted with a dilemma means having to make choices. Her use of the word 'struggle' highlights how difficult it is to progress the situation knowing that her decision will affect a number of people in different ways and that certain needs or perspectives will have to be prioritized. Katie implies that dilemmas can be of varying content. It appears that the frequency of dilemmas is understood as something that is particular to her job, which is that of a palliative care nurse specialist.

Like Katie, Claire talks about the difficulty and frequency of dilemmas. She talks about being pulled in many directions which leave her feeling confused and unsure how to proceed. The frequent pauses in the following extract as well as her repeated use of the words 'right thing/way' and 'should' seem to reflect Claire's hesitation and confusion:

⁵ Please see Appendix M for an explanation of the transcription conventions used and Appendix R for examples of edited quotes.

⁶ Quotes are referenced by participant and line number; pseudonyms are used to preserve participant anonymity.

Hmm, well it's when you're [pause] hmm, unsure [pause], hmm, you feel kind of in the middle, you're not sure [pause] whether [pause] this is the right thing and how it should be done or this is the right way and how it should be done. Hmm, [pause] something that can cause confusion [pause], hmm, god isn't that terrible, we're faced with [...] dilemmas every day. (Claire, 475-481.)

The repetition of the phrase 'we're faced with this every day' initially framed as a question and then stated as a fact suggests that Claire may not have been fully aware of just how frequently she encounters dilemmas in her work and the impact that these have on her. It appears as though she appraises this frequency as something negative.

Staff's discomfort evoked by dilemmas seems to be reflected in their reluctance to use the term 'dilemma' and their attempts to find alternatives:

No, I don't think, [the term] is used. I mean a dilemma or 'oh, this is a challenging situation' and 'I just need advice'. Yes, the sort of thing it does tend to be = (I:= Yeah.) either, or. (Claire, 522-529.)

Claire's suggestions for alternative ways of referring to a dilemma convey the impact dilemmas have on her; that is she feels challenged and requires support from her colleagues. It appears that she is making an attempt to share and reach out in order not to be left holding the dilemma on her own.

In the following quote, Katie implies that there are times when she may use the word 'dilemma' but that there are more appropriate alternatives. She reiterates that she encounters dilemmas in her work yet feels unable to use the term 'dilemma' and talks about 'those situations' instead. This seems to highlight her discomfort about the term which is further emphasized by alternative phrases she uses to describe a dilemma. Her use of the pronoun 'we' reflects that she understands these alternatives to be mutually agreed ways of referring to and talking about dilemmas amongst her colleagues.

Hmm, I probably don't use the word – [...] not on a daily basis – [...] We'd probably more talk about [pause] options [...] or I'm worried about something, I'm concerned I'm doing the right thing. (Katie, 373-377.)

Sarah is more explicit about her reason for choosing alternatives suggesting that the term carries a negative connotation and is likely to also be perceived negatively by her colleagues:

A 'dilemma' is probably not a very positive way [...it] sounds quite negative [...]. A 'situation' can be quite balanced and quite neutral, [...] if you [...] say 'I've got this dilemma', straightaway people might get their back up and go 'Oh, what'. Whereas with 'situation' it might be [...] 'Alright, ok, what's the situation?' (Sarah, 577-583.)

Sarah's interpretation of the term 'dilemma' suggests that the term implies a negative way of talking about a scenario and causes negative reactions. Her chosen alternative ('situation') is understood as a more acceptable way of talking about a dilemma. One interpretation of Sarah's account is that she relies on her colleagues to help her confront dilemmas and she therefore needs to create opportunities for discussion and problem solving; 'dilemma', however, risks evoking irritated and annoyed reactions thus depriving her of her colleagues' support. Sarah's understanding for the reason why the term 'dilemma' is likely to lead to defensive responses is further elaborated on in the following extract:

I think 'dilemma' might mean that somebody is to blame if there is a dilemma, whereas a situation has just occurred. (Sarah, 593-594.)

She implies that the people faced with the dilemma may have done something wrong that led to the dilemma and are therefore to be held responsible for their action. Fear of being blamed or held accountable prevents staff from working as a team and trying to work through the dilemma together.

One participant, Anna, talked more positively about dilemmas suggesting that they were intrinsic to her role as a therapist:

Dilemmas are just an – I guess, it's what I live with anyway as a therapist when you're talking to people and they're telling you [...] the narratives of their lives that [...] [pause] speak of dilemmas.
(Anna, 606-615.)

Anna appears to accept dilemmas as being part of her working life. In comparison to the nurses' accounts who feel inclined to try and resolve dilemmas, Anna feels comfortable in staying with dilemmas indicating possible professional differences in approaching such situations.

3.1.2 'Something's Stirred up in You'

A notable feature of how participants talked about their understanding of dilemmas was the way in which dilemmas were perceived as personally challenging and evoking an emotional reaction in staff.

Dilemma is where, hmm, something is not easy. [...] it basically is something's stirred up in you. (I: Mmh.) Something that's made you feel a bit uncomfortable, it doesn't sit right with you (Sue, 347-350.)

Sue's comment highlights just how difficult dilemmas can be for her. Her use of language suggests that she finds it difficult to shield herself from the dilemma and it appears as though she experiences a physical reaction leaving her feeling uncomfortable. She goes on to talk about her need to act in response to the discomfort she is feeling which appears to be exacerbated by the unexpected nature of the situation:

Also you might need to seek advice, you need to talk it through, something that's not going perhaps along with how you expect it. [...]. So [...].it's the unexpected or something that throws up a lot of

emotions as well, that actually challenges you, how you're going to deal with that.(Sue, 347-355.)

The emotional quality of dilemmas seems to be reflected in the repeated use of the second person pronoun 'you' which has the effect of creating a distance between Sue and the material, possibly because she finds it too difficult to bear. This is further elaborated in 3.3.2. Sue goes on to talk about the need to seek support from colleagues or other professionals to confront the dilemma, which supports this hypothesis.

If that happened [I] would be not carrying on alone, hmm, and it would definitely be in seeking support of my colleagues here or basically people with [...] more experience. [...] and also perhaps seeking someone else to come and work alongside you. (Sue, 361-367.)

Sue's account suggests that the emotional reaction invoked in her leads her to question professionalism and requires her to seek support and advice in order to clarify how to proceed. She also suggests that working with a colleague may enable her to hold on to her professional identity rather than being influenced by her personal views.

Like Sue, Paula talks about the emotional quality of dilemmas which makes it difficult for her to find a solution.

Something that challenges you very personally [...] that hits a heart string with you and takes you back to something that maybe happened to you but you've then got to keep it on a professional level. (Paula, 374-378.)

The metaphor Paula uses highlights the level of emotion evoked by the memory associated with the dilemma, which literally leaves Paula hurting as though her heart string was pulled. Paula alludes to having to contain and distance herself from the emotional response evoked in her in order to comply with the

expectation of her as a professional to remain objective. The need for objectivity will be further elaborated on in 3.1.3.

3.1.3 Negotiating Multiple Perspectives

This theme highlights the notion of negotiating multiple perspectives. Sarah's account highlights her struggle to make a decision about how to proceed knowing that it will impact on the family and given that her personal opinion conflicts with the perspective of the majority which is underpinned by professional guidelines.

[...] you're fighting with yourself over what's the best way and where should you [...] lead the family to and, [...] where do you stand in the meetings [...] when everyone else is saying 'Yeah, but the guidelines say'. (Sarah, 632-637.)

Her struggle is further highlighted in the following extract where it appears that she is confronted by a number of opposing opinions making it difficult for her to retain a bird's eye view and to remain objective rather than being influenced by her own personal opinion.

Yeah, the guidelines say and [...] the doctor's coming one way with her symptom management and [...] the community nurses coming another way and then you've got the family coming with one situation they want. And you've got [...] stand back and look [...] objectively at it [...] and then you've got your own opinions [...]. (Sarah, 637-645.)

Jenny's account suggests that dilemmas pose a challenge even when they do not affect her directly and it is not her who has to make the decision with regards to which option to pursue. There is also a sense that Jenny may disagree with other people's decision yet may choose to withhold her own opinion perhaps because she does not want to further increase the dilemma.

Yeah, it's when you've got more than one option, and you are not sure whether you or that other person is doing the right thing and in your

head they might not be. Yeah that is what I think is a dilemma, not sure what path to take. (Jenny, 782-786.)

Her choice of words implies that it is impossible to follow a 'good enough' path or reach a compromise. The image of Jenny holding her opinion in her head rather than voicing it may suggest that she feels uncomfortable with the idea of multiple, potentially opposing opinions or a need for her to be objective thus keeping her opinion to herself.

Claire's account implies her motivation to put the patient first when trying to resolve a dilemma and remind us of Jenny's idea of doing the right thing. However, she remains mindful of other factors that may impact on decision-making and the need to be objective.

And it's just really important, it's something you, you want to get right [...] do the best for [pause] that patient but take into account all the factors. (Claire, 484-486.)

David on the other hand contradicts the idea of doing the right thing by suggesting that this can never be achieved and that a compromise is inevitable:

There needs to be compromise [...] there are no easy answers to lots of these questions so sometimes it's about going with the best knowing that it's not right [...] what can we do [...] to support this family, that member of staff in the best [way] [...] we know we can't be perfect. (David, 474-479.)

David's comment emphasizes that in this field certainty is impossible to achieve and that ultimately not everyone will agree with the decision taken. Nevertheless, David highlights the need for objectivity in reaching a decision with regards to whose needs to prioritize by frequently using the word 'best'. Whilst he is motivated to reach the best possible outcome from a professional perspective he appears realistic about his limitations as a professional by acknowledging that care can never be perfect.

3.2 Greater Perspective on Life

This theme conveys the participants' heightened awareness of the finality and preciousness of life as a result of working in paediatric palliative care. Building long-term relationships with families provided unique insights into families' lives which participants experienced as enriching through a greater appreciation of their own lives and which help them to cope. However, participants' struggle of living an ordinary life was also recurrent across their accounts as was a need to be realistic about their remit and potential contribution to families' lives.

It sounds so stark [pause] but it's great that we have a sense of purpose in our life, [...] we can feel useful, [...] make connections with people [pause] hmm, and I think [pause] between living and dying we [...] have our best with a bit in between. And that can be so much.
(Anna, 385-389.)

3.2.1 Being in a Unique Position

A striking theme was staff's expressed appreciation of working with families of children with LLCs. Supporting families along their journeys allows staff to occupy a unique position. In the following account Jenny talks about her realization of the nature of the work both with regards to the families' circumstances and the staff working in PPC.

It was a shock [...]. It was unfolding as I was doing [the work], I probably didn't realize [...] what I was letting myself [...] I had no idea children were that sick, [...] people outside they don't know what goes on (Jenny, 162-166.)

Jenny's comment was made in the context of a question about her pathway into PPC which arose out of a necessity to find work and her motivation to work with young people rather than any previous experience in palliative care. Jenny talks about the early stages of getting used to her new role as a distressing process which gradually offered her painful insights into the reality of PPC. She implies

that PPC is like a separate world that she had not previously inhabited like the majority of people who will never be privy to it.

She goes on to talk about her discovery of the 'new world' and its inhabitants which include not only the families but also the staff who work in PPC. There is a sense that she has undergone a transformation from feeling an initial reaction of shock to being astonished and full of admiration and that her new role has been a revelation.

This is a new world here, I never knew it existed. Marvellous. The team what they do here is just an eye opener really. I didn't know these people existed. (Jenny, 170-172.)

The notion of rare insight into a different world is echoed by Anna. Whilst the term 'privilege' makes her feel uneasy as though it was diminishing the experience of the families she supports she highlights the uniqueness of her work:

It just sounds so cheesy, this whole sense of privilege. But there is a sense that we are in a unique position. (Anna, 310-311.)

Paula on the other hand is more comfortable with the term privilege implying a sense of pride and honour in her role as clinical nurse specialist:

I've always, always felt a huge privilege [pause] to work with families who have a child with – you know – a potentially life-threatening condition (Paula, 132-134.)

The following quote highlights to the often uncertain life-death trajectory of the children meaning that death is not always imminent and services are required for a long period of time. Whilst this enables the building of long-term relationships, Paula remains aware that the children's life expectancy is limited. She talks about travelling alongside families for a substantial amount of time by employing a 'journey' metaphor but that their time is ultimately bound by the inevitability of the child's death.

You get to know families over a quite a long period of time, certainly during that journey that, that families are on, hmm, when they've got a very sick child. (Paula, 128-130.)

Anna alludes to the strain of the work brought about by a heightened awareness of death which is further explored in 3.2.3, but she feels impressed by the families' strengths to cope given their circumstances. This is highlighted in her description of 'ordinary people' which contrasts with their ability to do 'the most amazing stuff'. Her unique insights make her question her own ability to cope under similar circumstances.

This is a tough job that we're doing, hmm and we're all doing our best and, I think, parents are [pause] absolutely brilliant. I have no idea how I'd cope if it happened to me [pause] but I see ordinary people doing the most amazing stuff in their lives. (Anna, 286-289.)

There is also a notion that staff are sustained by the uniqueness of their experiences:

[The families] they are just wonderful and really that is what keeps me every day in this organization (Jenny, 248-250.)

It is as though the unique insights gained as a result of the families' generosity and willingness to allow staff into their lives and share with them provides nourishment and fulfillment as suggested by Anna below. This in turn enables staff to continue in their work but also to feel part of a meaningful cycle of continuous learning and development through being with and giving back to families.

I suppose I get fed and rewarded by adding to my knowledge of people adding to my skills, [families] show me things like how they live their lives [...] when they're at their most vulnerable. And [pause] are willing to share what goes on in their lives. So, if I can use that to help

them and to help other people then I feel as if I'm part of a chain [...]
(Anna, 322-328.)

3.2.2 Knowing What is Important

A process of reflection by participants on what they valued in their own lives contributed to their perspective on life. This was evident in statements staff made about their heightened awareness of death which led them to focus on what was important in their personal lives and at work.

[...] the most obvious thing is obviously you see these children and you lose them and obviously it makes you as an individual appreciate what you've got. (Jenny, 707-709.)

This extracts highlights that staff's experience of a child's death at work can lead to a process of reflection on their own lives. My understanding of Jenny's comment about herself 'as an individual' refers to both her personal and professional identities which are ultimately connected and interwoven. She therefore implies that her increased appreciation spans both her personal and professional lives. This appears to be linked to section 3.3 which explores staff's movement between personal and professional identities as a way of coping with dilemmas.

An increased appreciation of positive aspects in staff's lives in the context of their experiences at work is also highlighted by Paula:

I think [working in PPC] probably made me more appreciative of my own family [... through] the knowledge of having first hand experiences of [...] the turmoil [and] sadness [parents] go through, the difficult lives that some of our families live [...] it makes you realize that you take a lot for granted (Paula, 325-335.)

Having 'the knowledge' encapsulates a heightened awareness held by staff of the havoc created by LLCs and its devastating impact on families which leaves them

struggling and reeling with pain. It is as though Paula finds it difficult to contain the ripple effects of the chaos and sadness and therefore her only way of shielding herself from the families' pain is to turn the gaze towards her own life and to remember what it is that is important to her, i.e. her family. Paula's account speaks of guilt about a perceived insufficient appreciation of her own life as well as a notion of taking things for granted. This is further explored in the next section 3.2.3.

Like Paula, Anna talks about an increased appreciation of life brought about by her heightened awareness of the finality of life:

It's just a knowledge that's hard-won that [...], life is precious! [...] a quiet knowledge that [...] we're here, we do the best we can and then we die. (Anna, 376-383.)

It appears as though Anna had to fight a tough battle which symbolizes the challenging experiences of working in PPC before she was able to arrive at a point of acceptance that life is time-limited. Her realization that life provides an opportunity to do one's best seems to represent her winning the battle.

Anna goes on to talk about the impact the heightened awareness of death has had on her. The following extract implies that working with death has led her to question her very existence and magnified who the most significant people are in her life and what things are most meaningful to her.

This quiet knowledge that sits with me about who I am, what I'm about, who are the important people to me and what, what REALLY [pause] what are the important things in life. (Anna, 418-420.)

Having a greater awareness of life and death not only seems to increase the participants' focus on what is important in their personal lives, but also shifts their perspective with regards to what is important in their working lives. Tim as an example talks about the importance of remembering that small things can have a significant effect in the context of limited resources.

You know, [...] it's the little things that count. And I get frustrated sometimes when I feel that people forget that. (Tim, 363-364.)

Sarah echoes this notion and implies that it helps her to resist the pull of getting side-tracked by attending to what she refers to as 'other issues'. Her account highlights her awareness of the preciousness of life which is magnified by the girl's limited life-expectancy. Perhaps she is a representation of Sarah's knowledge of the finality of life gained through her work with other children with LLCs. This leads Sarah to a deep appreciation of what matters for this girl and her as a professional, that is to share experiences that are profoundly special and yet very ordinary.

The child might have all these other issues and you're dealing with them for four hours [which] could be spent out in the garden. And, you just think [This] is the best thing [...] to see her, like seeing them smile or enjoy, [...] being outside and feeling the wind for the first time. (Sarah, 988-993.)

Those things [...] are] worth everything. They're worth the weight in gold. (Sarah, 1002-1005.)

The following comment by Tim captures staff's shared appreciation of what is important in their working lives in the context of their heightened awareness of death, that is an emphasis on being with families rather than doing:

You don't have to give them a gold framed wheelchair, [...] what you need is, [...] the presence of you (!: Yeah.) and [...] the people who are working with that family. Making a cup of tea, having a chat with them, that isn't directed at care. (Tim, 346-356.)

3.2.3 Skewed perspective

Whilst staff's unique position provides meaning and purpose in their lives, participants also alluded to experiencing conflict as a result of their heightened awareness of death with regards to their personal lives. This subtheme conveys participants' struggle to live an ordinary life in the context of their heightened awareness. Staff talk of the struggle to allow themselves difficult feelings in their personal lives without feeling guilty about losing a greater perspective on life and taking things for granted.

I have a [pause] profound appreciation of the moment of life. [...but] it gives you a skewed perspective that [...] when I'm getting irritated because the plumber hasn't arrived [...] I'm so aware of the extremes of my professional life, of witnessing and helping people through [...] the process of how they deal with their dying child, so death and dying thoughts are never far away. [...] I'm just so [aware of] the preciousness of life. (Anna, 359-373.)

Anna's term 'skewed perspective' implies an imbalance that puts staff at risk of diminishing the value and importance of their personal day-to-day struggles in comparison to the significantly greater life-death experiences they witness at work. Like Anna, Sarah suggests that work provides a greater perspective on life which creates a tendency to compare her personal worries against those of the families she works. On the other hand, Sarah emphasizes the importance of acknowledging the divide between her personal and professional life thus allowing herself to value and express her worries; on the other hand, acknowledging her personal worries leaves her feeling guilty and as though she was absorbed by self-pity.

You come into work and you think 'Ah, what am I doing whinging about this, [...]. But, [...] I should allow myself to give out about those kind of things [...because...] outside of work they are [...] a worry to me. (Sarah, 359-368.)

Staff's struggle to live an ordinary life is further reflected in the extract by Claire who refers to 'two sides that kind of flip'. She alludes to having both insight which leads to a greater appreciation of what is important in life as well as outside that is an appreciation of the value and magnitude of her personal life in relation to her working life. This creates tension and feelings of guilt. She emphasizes the need to acknowledge that she is only human thus giving herself permission to feel and be affected by experiences in her personal life.

It does make [you] realize – that life is too short [...] I say that on the one hand, but on the other hand, there's things that I moan about. So I think 'why are you moaning?' [...] There's kind of two sides that kind of flip [...] but [...] I try not to give myself a hard time over it. Whatever goes on in your life, it affects you. You know we are human beings with emotions and feelings (Claire, 342-359.)

3.3. Moving between the Professional and Personal

The way in which participants described their ways of coping and making sense of dilemmas encountered at work indicated a constant movement between the professional and personal realms implying a lack of division between staff's personal and professional identities.

3.3.1 Professional Identity

Many accounts emphasize the importance of staff's professional conduct and competence as providing guidance and reassurance when confronted with dilemmas as exemplified in the extract below by Sarah:

Nurses are governed by the NMC. [...] all you hear about is the code of conduct [...] in everything you do [...] really they are our rules and [...] it's very clear, [...] what we are allowed to do, [...] we can't just do things because we think we can do it. (Sarah, 160-168.)

Sarah's account implies the significance of her professional code of conduct as underpinning and prescribing every aspect of her practice as a nurse. Whilst it appears as though the 'code of conduct' provides clear guidance and structure she also makes reference to it overriding her personal views.

Like Sarah, Claire talks about drawing on the professional code when confronting dilemmas and the need to work within her professional competence. The following comment was made in the context of her talking about a dilemma which arose as a result of a nursery's request to provide teaching on accurate methods of suctioning for a child who was under their joint care. Whilst Claire did not feel competent to provide training or perceive this to fall within the remit of her role she was in the process of seeking expert advice to clarify her position. However, she was aware that her perceived refusal to train nursery staff meant that the child was at risk of losing his nursery place and strained her working relationship with the staff and family.

I [was] taught that you need to be [pause] confident, competent in what you're doing [...] and you need to have the correct knowledge [...] to pass that information on. And I don't feel like I've got that kind of knowledge so I feel that why I'm doing this is right. And I think that's been backed up by the advice of [...] the team and the medical director. [...] I'm ok to go up to here but beyond that, [...] I'm not, [...] sticking to my professional code of conduct. (Claire, 1155-1175.)

Whilst the dilemma left her feeling unsure how to proceed, the extract highlights her tendency to draw upon her professional identity as a nurse to reassure herself that she was acting within what she perceived to be her professional competence.

Another shared way of approaching dilemmas was that of prioritizing the needs of a child and safety concerns over staff's relationship with families. Sue talked about her dilemma of insisting on safe feeding practices at the risk of jeopardizing her relationship with the child's mother.

We had to address [...] feeding via gastrostomy because it wasn't a safe practice. [...], my role was to go in and instruct our carers [...] basically we're taught to do it one way by gravity but this mum was actually forcing the feed in (Sue, 408-419.)

It was the safety issue of the children which was [a] compromise to our practice [...] – you had to balance out child protection and [...] that if you didn't keep [...] a foot in the door what would be happening? (Sue, 661-670.)

Like Sue, Katie talked about being in a dilemma with regards to whose needs to prioritise. She talks about drawing on her duty of care for the child which needed to take precedence over her wish to preserve a good working relationship with the family who Katie believed to be neglecting her child.

So I had to make that decision [to raise this as child protection] [...] and obviously [...] I was upset, [the family] were upset [...] and I wanted to protect that family although I'd done THIS. I needed them to know [...] because I'm the one who built up that relationship and I ruined all that now. (Katie, 454-462.)

The extract highlights Katie's struggle to live with the consequences of reporting her concerns about the mother's inadequate care for her sick child to Social Services. Although Katie's comment implies that she considered her decision to raise her concerns an absolute necessity and a means of protecting the family, she experienced her decision as incredibly challenging. There is a sense that she had invested so much in the relationship with this family that her decision felt counter-productive and destructive and left her feeling emotionally drained.

3.3.2 Personal Identity, Values and Beliefs

This theme conveys a notion that staff draw on their personal identity, values and beliefs to help them make sense of the dilemmas experienced at work. These are

additional to professional frameworks which facilitate coping which were discussed in the previous section.

In the following extract Claire talks about drawing on family values instilled in her as a result of her upbringing when asked about what frameworks, beliefs or values she draws on to help her make sense of dilemmas encountered at work.

- P: One [is] 'don't do to others what you wouldn't do to yourself'.
Another one is 'be honest and truthful with yourself'. [...]*
- I: And [...] where would you say they stem from?*
- P: Hmm, probably my upbringing, the way I was brought up.*
(Claire, 1194-1205.)

Although Claire shared her surprise and increased awareness of how influential her family values had been on her sense making of dilemmas there seemed to be a continuous thread running through her interview that highlighted the influence of her mother and early experiences of working with children with learning disabilities on the formation of her carer identity and nursing as a career choice.

I just always had that yearning to sort of want to help [...], I think in some sense [pause] there's, hmm, something about me that [...] I just want to sort of [...] reach out to them and do as much as you can to improve their lives, quality of life. (Katie, 157-169.)

Jenny talked about her role as a youth worker which involved running a social group for young people with LLCs which had a relatively poor uptake despite the young people's expressed wish to socialise with peers. Jenny had a sense that the lack of attendance was linked to parents feeling overprotective and finding it difficult to let go of their children whom had always been dependent on their care.

We all find it difficult letting our children go and I can't even imagine how much more difficult it is to them so I have quite a lot of empathy with that feeling and that is probably why I'm not so pushy. I don't sort

of say [...] [the group] is the best, they would LOVE it, [...] because I just, I know how I'd feel if someone told me that I would have to let my child go to this group (Jenny, 923-929.)

Jenny goes on to talk about drawing on her identity as a mother to make sense of her described dilemma:

[...] it is my own experience as a mum [...] I've not lived their experience but I've made sense of it because I think of myself in that situation. (Jenny, 1101-1104.)

She sides with the parents' struggle to accept their children's growing autonomy and independence by drawing on a collective identity and shared experience of being parents. At the same time she acknowledges that their experience is not the same given that she does not have a child with a LLC and therefore cannot ever fully understand their experience.

Anna talked about multiple dilemmas in her role as a therapist. These included difficulties of meeting the needs of families in the context of limited resources and negotiating conflicting ideas by different professionals within the hospice about the appropriate time frame for offering support to families.

My belief is a semi-spiritual one that says [pause] 'If you have a skill, if you can, of connecting with people, then use it'. Hmm [pause] the spiritual bit comes in that 'we're only here for a short time, make the best of it' (Anna, 1210-1213.)

Anna definition of her belief as 'semi-spiritual' seems to suggest that she drew both on her personal and professional identity to think about and cope with these dilemmas. The spiritual element seemed to encompass an awareness that life was finite which helped Anna find meaning and encouraged her to strive towards doing her best in life. At the same time Anna seemed to belief in her skill as a therapist which enabled her to build relationships and maximise the opportunities with families encountered in her work.

Tim echoed the notion of maximising rare opportunities in the context of discussing an ethical dilemma. Tim decided to take steps to extend a child's care without doctor's guidance rather than let the child die in the absence of his mother.

I believe in the idea that if something is at your disposal and you have the opportunity to make a positive contribution, you should do so (Tim, 1238-40.)

Tim also drew on moral values in helping him to make the decision by stating 'it just felt the right thing morally, [...] if I had to make that decision for my own family I would make that same decision' (1252-55).

The extract below illustrates how one member of staff, Sue, drew on her Christian faith to help her cope with a parent's abusive responses and disengagement in response to Sue raising child protection concerns about the mother's unsafe feeding practices.

I'm Christian and we're taught to love everybody, no matter what they're like and I think that's part of my philosophy [...] 'God loves everybody. Christ showed love to some difficult people', [...] so I presume, I have quite a high tolerance level. (Sue, 731-735.)

Sue adopted a Christian philosophy to resist the temptation to disengage and instead made continued effort to preserve and rebuild the working relationship with this family. Her faith also seemed to help her develop an acceptance of the dilemmas encountered.

Acceptance seemed echoed in Katie's way of coping. Whilst she talks about the injustice of children dying she accepts that death is part of life. Although she seemed less sure where this stemmed from she implied a link to her upbringing and belief in god.

I suppose I have an acceptance, [...] it's not fair and it's unjust because they are so young and they suffer [...] but it happens [...]. And that's not through anything [pause] I particularly believe [...] I mean I was brought up going to church and [...] aware of god [...], I'm pretty sure he does exist. (Katie, 725-735.)

3.3.3 Creating a Distance – Self-care

This theme captures the way in which participants draw on coping strategies to help them cope with the dilemmas experienced at work. Staff accounts suggest that their work with families creates proximity requiring them to establish physical and emotional boundaries from work to help them cope.

If I am looking after myself, then I don't think there is any need for [feeling burnt out] but also [...] if I am not looking after myself then I'm not going to be looking after the people I'm entrusted to look after or to walk alongside. (David, 351-355.)

David's comment encompasses a notion that staff develop a close bond with the families they work with and that this makes adequate self-care not only a necessity but also a responsibility to ensure staff can provide continued care.

In the following quote, Sue alludes to the notion that work in PPC creates proximity and makes it difficult yet necessary to maintain boundaries both in the interest of the family and herself.

When the child is in that end stage or has died and the family [...] is absolutely distraught. It's no good you being distraught. [...], inside you are but you have to somehow build up coping strategies to then when you come out, [...] there are times when you do cry with families but [...] you don't want to be in floods of tears [...] But [...] you don't want to show that you're hard either. (Katie, 296-307.)

Sue highlights her struggle to detach herself from the experience in order to provide support to the family making it necessary to express her distress privately. At the same time she worries about being perceived as emotionally cold if she fails to reveal a certain level of emotional connectedness.

However, it is not only about creating an emotional distance as evident in Anna's comment. She talks about the importance of taking regular holidays as a means of creating a physical boundary from work which is necessary to enable her to take her mind off work:

[...] I physically have to get away, so I may be in another county or another country – but I always make sure I get away. (Anna, 1132-1135.)

This is echoed by Sarah who talks about the need to take a break after a prolonged period of stress induced by a dilemma of whether or not to meet a request by parents to discharge their child when professionals shared concerns about the family context and home environment.

I knew I needed a few extra days [...] before [...] I would have said 'Well no, I have to come back to work, [...] it's a weakness to say that I'm not able to cope'. [...] now I'm able to recognize that [...] it's a strength [...to] know that if I come back early I'm going to not be [...] able to cope with it. (Sarah, 1254-1260).

Sarah implies that in the past, expectations of professionalism have led her to think of herself as weak when struggling to cope with dilemmas and that she is now able to resist such discourses. She suggests that she has arrived at a place where she is able to recognize and set herself limits which she perceives as a strength rather than weakness and increases her ability to cope.

Participants' accounts suggest that staff have a number of ways to look after themselves. The benefits of socialising with friends or engaging in leisure

activities are highlighted by Claire in the following extract. Self-care activities seem to help staff to take themselves away, process their experiences or distract them from work related things thus helping them to feel less stressed and cope better.

I've got a good network of friends [...] sometimes you know just jumping in your car and getting home [...] and everything you think of [goes] through your mind. [...] obviously going to sports [...] help take your mind off things. Doing arts and crafts, [...]. Watching a bit of TV, [...].can sort of just support you in dealing with [...] a whole working day. (Claire, 1262-1274.)

However, not everybody perceived social support as helpful. Katie for example talked about her struggle to escape her professional identity in the home setting. She struggled to feel understood and communicate her needs to be listened to and cared for and thereby failed to create the distance from work that appeared necessary for coping.

Brilliant family, hmm, who will listen but they're all going through difficult times [laughs] at the moment so I'm supporting them and I do often see [...] that I'm often seen as the nurse and the supporter and [pause] that's my role. (Katie, 941-945.)

3.3.4 Blurring of Professional and Personal Identity

Whilst the previous sections talked about professional and personal resources and coping strategies as separate entities, this theme captures the way in which staff seemed to constantly shift between their professional and personal identities and frequently drew on relevant resources and frameworks adopted from both realms to help them make sense of their dilemmas.

David implies that the desert, i.e. his personal life, helps him to cope in the market place, i.e. work. However, due to the demands of his work he is required

to retreat to the desert to process his experiences and recharge before returning to the market place.

My time I've spent in the desert enables me to be in the market place but actually what I learn in the market place I have to take back in to the desert and make some sort of sense of that so you can continue to do that work. (David, 423-427.)

A lack of division between the personal and professional was consistent across participants' accounts.

You are two people but [...you] overlap, there is certain parts of your character that come to you as a nurse and there is certain parts of your nurse that comes through in the outside. (Sarah, 380-383.)

Sarah implies that staff's personal and professional identities are closely connected and interwoven and that her nursing identity is displayed both on the insight, i.e. work and the outside, i.e. her personal life.

This idea is supported in the following comment made by Paula who goes one step further and suggests that the interconnectedness of staff's identities is not only unavoidable but actually necessary. Paula implies a conscious process of revealing aspects of her personal self in order to engage with and sustain positive long-term relationships with families.

I don't feel like professional boundaries are crossed in any way – but I do think it is really important to [...] give the parents a little glimmer of yourself in order to maintain a really good relationship. (Paula, 899-902.)

Claire also alludes to the blurring of personal and professional identity but implies a less conscious process of revealing her personal self which she suggest takes precedent over her professional one.

Yes, I suppose we're professionals but at the end with are human beings I suppose. You're always human being before you are anything else, maybe. (Claire, 1241-1243.)

3.4 Sharing the Burden

This theme conveys the value staff placed upon using different sources of support in an attempt to share the demands of the work which they frequently perceived as a burden and to facilitate coping with dilemmas experienced in their work.

Just sharing the experience with other nurses, our line manager the doctor that works here [...is] very, very helpful [...] because I didn't feel then that I was holding the burden of it to myself. (Paula, 941-945.)

The theme incorporates the variation in staff's perspectives on support structures on offer to them and encompasses staff's wishes to connect with and support each other as both human beings and professionals.

3.4.1 Creating a Shared Understanding

Staff accounts highlight a number of support systems on offer which included (in)formal peer support, individual clinical supervision, internal and external group supervision, support and supervision by management and external support via a telephone helpline. The provision of support varied across the two settings and in its formality and structure. The comment below exemplifies a notion that support structures are essential in helping staff to cope whilst acknowledging differences in the way members of staff use support and perceive certain types of support as beneficial or suitable to their needs. David highlights the importance of giving staff an element of choice with regards to what support works for whom.

[Staff support is] absolutely crucial. But you know [...] people [choose] who they talk to, there needs to be a whole menu. (David, 303-305.)

A unanimous theme across participants' accounts was the value of informal peer support which provided an essential way for staff to share and talk through their dilemmas with each other and develop a sense of a having shared understanding with their colleagues.

We talk about the obvious with other members of staff; you know 'do you think I'm wrong? [...] And am I wrong in not going into the nursery while I've been asking for advice?' [You] get real reassurance in that sense. (Claire, 972-977.)

Claire's comment took place in the context of her talking about what had helped her in managing the previously discussed dilemma she had experienced at work. It highlights the benefit of sharing with colleagues as a means of gaining comfort and encouragement with regards to her professional remit and responsibility.

Sue talks about ad hoc peer support as an essential way of coping with dilemmas especially when most of her clinical work takes place in isolation during home visits. She emphasises the importance of a supportive working environment and time to share when returning from families' homes.

Informal supervision with colleagues [...is important...] you're always going back to base and discussing difficult situations with your colleagues and having the time. (Sue, 752-755.)

The following quote by Katie echoes this notion of feeling reassured by the knowledge that her colleagues will be available to her if she needs to share her worries or concerns. She implies a shared understanding amongst her colleagues that their work can be challenging and peer support is an essential way of managing this. There is an overriding sense that her needs will be acknowledged and met by her colleagues and take priority regardless of time pressures.

I KNOW that I can talk to anybody in the team (I: Mmh) we're all extremely busy but [...] [people] will recognize that there's something wrong [...] people will stop and listen to you [...]. (Katie, 827-833.)

In addition to informal peer support from nursing colleagues, the value of both formal and informal support from senior members was prevalent across many interviews.

And then you have [the family support worker] who you can [...] talk to whenever you have a problem, you [...] just say 'Can we have a chat?' and speak to her. (Katie, 1473-1476.)

Hmm, I know [my manager's] door is always open. (Claire, 1254-1256.)

Both these extracts illustrate that staff felt able to seek support from senior members of staff as and when required as they were perceived as approachable by modeling an 'open door policy'. This created a supportive team culture that filtered down from management level across the whole team. Having a supportive manager seemed to form an essential source of support through informal sharing as well as regular allocated slots for management supervision.

Sue talks about the importance of feeling supported, affirmed and backed up by her manager in the context of the dilemma she experienced and her attempt to re-establish a way of working with the family after raising her concerns about unsafe feeding practices to social services.

[To] be totally backed up by [her helped...] [and] she was willing to go in and do this initial setting up which I usually never need. (Sue, 889-895.)

Many participants spoke of the value of a helpline which was on offer in the children's hospice and meant that staff could access an external support

structure 24 hours a day for advice and support for any issues which arose in both their working and private lives.

The phone service [is] really useful. Because that's more than just about work, [...] that's a positive thing [...] that's very useful. (Tim, 1439-1444.)

There was a sense that this type of support system was beneficial not only because of its anonymous nature but also because it indicated a recognition by the service that staff were not merely professionals but also had personal lives. Support that encompassed aspects of both their personal and professional lives were valued.

The benefits of an external anonymous support structure resonated with staff at the community hospice service for the very reasons. The term 'offloading' alludes to the benefit of talking which decreases the weight of the work that is perceived as a burden.

There should be an external service that you [...are...] able to offload to if you have got a problem because even though offloading does happen here [...], I still think that people would offload more if it was done in completely anonymity. (Jenny, 1351-1355.)

Another source of support, though not unanimously discussed, was that of additional counselling or clinical psychology input for family members that were supported by the nursing staff. Two members of staff spoke of an identified need for additional family support and their awareness that parents' needs for psychological support was beyond what they perceived to be their professional remit or skills. Both staff felt this additional source of support would have helped them to cope with and resolve the dilemma more easily.

I spent [...] weeks looking for a psychologist that would deal with autistic children, couldn't find [one ...]. Mum was supporting the family [...but] who did she have to go to and download all her problems with?

I mean we're not psychologists, [...] I felt she needed someone to go through these feelings and allow herself to feel the guilt of everything that was going on. (Sarah, 1077-88.)

3.4.2 The Value of Clinical Supervision

This theme highlighted the importance of clinical supervision as a means of supporting staff in PPC. Sue also highlighted the value of group supervision providing an opportunity to reflect on dilemmas and develop a shared understanding of each other's challenges and struggles creating a greater sense of cohesion within a team:

[...] we have regular monthly supervision facilitated [...] out of this building with somebody out of the organisation, we can talk, our manager's not there so [...] we always bring dilemmas to be honest [...]we [...] all have our say about it or just listen and support each other [...] we realize, [...], we're all going through difficult situations in very different ways but at least staff are then aware if you come into the office and you look absolutely dreadful, [...] they've got an understanding. (Sue, 755-774.)

It appears as though the team felt valued and invested through the provision of group supervision facilitated by an external facilitator as opposed to an internal member of staff. Staff were given an opportunity to make connections with each other and develop a sense of shared understanding and ownership of the space. There is also an idea that the benefits of group supervision continue beyond the actual group space and filter into everyday working lives by enabling staff to have a greater awareness of each other's needs and create an increased sense of interconnectedness.

This was echoed in the following comment by Paula who discussed the benefits of monthly group supervision:

It gives the nurses a chance to unburden some of their feelings to each other [...]. We all do try and go, whoever is in goes. [...] our line manager isn't there so [...] that is constructive [...]. The [facilitator...] kind of weedles things out of people [like] 'How do you feel about that?' (Paula, 976-987.)

The notion of group supervision as a means of establishing trust and a supportive team culture is echoed in the extracts below by David and Anna:

If you can get a team in a place where they can trust each other to [make use of] group supervision you are a long way along the road that actually achieving something very special. (David, 1131-1134)

One is to create a team culture that will look after one another (I: Mmh.) that you won't feel weak and vulnerable when you say 'you know what, it's just a tough day can I, can I do something else?' (Anna, 978-982.)

Both extracts illustrate that trust was perceived as an essential ingredient for fostering a team culture where honesty and openness was considered a strength rather than a weakness which enabled staff to have a better sense of each other, step in to support each other and truly work as a team.

Some divergence was evident in participants' accounts with regards to what constituted 'proper' or 'good' supervision. David drew a distinction between clinical and managerial supervision with the main ingredient of the former being reflection and of the latter being case management (1080-82.) Drawing on his long-standing career and experience of managing nurses in PPC, David created a context for a lack of historic investment in and clarity around the need of providing reflective clinical supervision for PPC staff. The quote below highlights David's understanding of the essence of helpful supervision:

Supervision is about going along and talking about the encounters I have had where the hairs of the back of my neck have stood up and I

have felt a bit uncomfortable and I haven't been able to make sense of it and so sitting down working through that trying to make sense of that so again the next time that happens [...] we'll be [...] more present and not distracted. (David, 1083-1089.)

Sue spoke of her experience of having previously received supervision facilitated by a Clinical Psychologist in her previous though equivalent role as nurse specialist in PPC and highlighted its lack in her current team:

Input from a clinical psychologist, [...] made me look at things in quite a different way [...]. But also having [...] one to one [...] what I call 'proper' clinical supervision which is reflective [...] within this team we have a need for clinical psychology input because [...] there's counselling, but [...] we could] do better by having some 'proper' clinical psychology input [...] you've got to be pretty expert at group supervision as well. (Sue, 963-983.)

Sue's comment highlights the lack of individual clinical supervision. Whilst acknowledging the value of individual management supervision she implies that clinical supervision is an invaluable and necessary space to reflect and think through her practice. Sue alludes to this through her use of the word 'proper', which also refers to clinical psychologists' training and competency thus making them suitable candidates for the provision of staff consultation and supervision.

3.4.3 Space for Connecting with Each Other

Although participants' accounts highlighted that both teams on the whole were well supported, some ideas were expressed with regards to ways in which a holistic team culture could be promoted and further enhanced. These included suggestions about protective lunch and break times, which '*would be good because it could be like the refresh button, I think you would come back to the job more rejuvenated*' (Jenny, 1370-1387); improved office facilities with the cramped

premises of the community hospice team considered '*not a healthy place to work*' (Katie, 983); and, subsidized gym memberships (Katie, 964.)

Most participants spoke of their desire to create more opportunities such as away days or team lunches which enabled staff to interact in ways that facilitated non-work related conversations. There was sense that this was vital in increasing their understanding and sense of connectedness when encountering each other in a professional remit. This links to the previously discussed theme 3.3.4 which highlighted that staff's multiple identities are closely interconnected.

[...] we're trying to organize an away day [...]. And in fact [...] a couple of months ago [...] we just all went out for lunch together and tried not to talk about work. [...] learning more about each other [...] is important. Knowing where we come from, hmm [pause] and just to recognize [...] so that you're not just nurse but actually, you know, you're seen for who you are rather than what you are. (Paula, 1028-1043.)

[...] once people get stressed they become less nice [laughs]. [...] I think to send [staff] away and to let them spend some time together, not as people who work here, but as people who are just people would strengthen that team a lot. (Tim, 1447-1455.)

Both of the above extracts illustrate the notion that staff would value time to make personal connections with each other which extend beyond the realm of their professional roles. Staff suggested that this would allow staff to get to know each other better and as a result increase cohesion and reduce stress and pressure felt amongst team members particularly in the context of demanding and stressful working environments.

4 DISCUSSION

This chapter begins with a summary of the analysis followed by a discussion of the ways in which the research questions are addressed by the study's findings and how they are situated in the existing literature. The discussion then turns its attention to the implications for further research and clinical practice before ending with a critical review and personal reflections on the study.

4.1 Summary of Analysis

The theme 'Dilemmas: Familiar Yet Uncomfortable' illustrates that dilemmas form an intrinsic part of staff's everyday working lives. Dilemmas were commonly perceived as challenging and causing confusion. A particularly notable feature was the way in which dilemmas were perceived as personally challenging and evoking emotional reactions in staff. Dilemmas frequently left staff questioning their professionalism and as a result they felt compelled to seek support from colleagues to clarify their position or to distance themselves from the emotional response evoked in order to comply with what was expected of them as professionals. The impact of dilemmas frequently led to a negative appraisal of and a reluctance to use the term 'dilemma'. The notion of being impacted upon and wishing to share with colleagues was consistently voiced by participants and led to mutually agreed alternative ways of referring to dilemmas; alternative suggestions included 'problem' or 'situation' which seemed to facilitate opportunities for problem solving and discussion with colleagues. The term dilemma on the other hand was associated with blame and defensive reactions thus depriving staff of colleague's support. Divergence from the negative connotation of dilemma shared amongst nursing staff was noted in the therapist's account. She considered dilemmas to be an intrinsic part of her work with families and felt more comfortable in staying with as opposed to trying to find a resolution to dilemmas which suggested potential professional difference in approaching dilemmas. A notable feature causing discomfort amongst staff was their struggle to negotiate multiple perspectives and make decisions about how to proceed. This struggle was particularly evident when their personal opinions conflicted with

the majority underpinned by professional guidelines or threatened their ability to consider various viewpoints. Staff were motivated by achieving best practice and putting the family first but expressed different views about whether certainty could ever be achieved and whether the need to compromise was inevitable or not when confronting dilemmas.

Staff's experiences of working in PPC put them in a unique position of gaining insights into a world which remains unknown to most people. Building long-term relationships with families enabled participants to gain unique insights into families' lives. Staff experienced the uniqueness of their experiences as sustaining and beneficial in helping them to cope. Being confronted with death and having an awareness of the impact caused by LLCs on families led staff to reflect on what they valued in their own lives and helped them to focus on what was important in life thus contributing to a 'Greater Perspective in Life'. Staff talked about having to confront the fact that life is time-limited and that this led to a greater appreciation of important people in their personal lives. There was also a sense that it magnified what was most meaningful in their working lives such as the significant impact of small and ordinary things in clinical practice and the emphasis on being present as opposed to care-directed activities with families. However, there was also a recurring theme of conflict experienced by staff as a result of their unique position and heightened awareness of death. This created a 'skewed perspective' which put staff at risk of diminishing the value and importance of day-to-day struggles in their personal lives in comparison to the life-death experiences at work which were perceived to be of a greater magnitude.

The theme 'Moving between the Professional and Personal' illustrates multiple ways in which staff attempted to cope and make sense of the dilemmas encountered in their work. Participants' accounts demonstrated that staff frequently drew on their professional identity for guidance and reassurance. Decision with regards to which option to pursue were commonly led by staff's professional code, competence and duty of care for children even when these risked jeopardizing their relationships with families or other professionals. In addition to that, however, staff talked about being influenced by aspects of their

personal identities. Identifying as a carer or mother or having a strong sense of one's upbringing and family values seemed to help staff make sense of their experiences. Although not consistently voiced, a few participants also drew on spiritual beliefs or their faith to help them make sense of dilemmas. All staff talked about the importance of self-care as a necessity and responsibility. The nature of PPC seemed to create proximity which required staff to establish physical and emotional boundaries to help them take their mind off work and prevent them from becoming enmeshed with families. However, in reality the division between professional and personal identity was less clear cut. Staff reflected on how their identities were inter-connected and overlapped and the importance of acknowledging their human side; there was also a sense that revealing aspects of their personal selves formed an essential part of engaging with families.

Finally, the analysis highlighted staff's engagement with various sources of support which helped them to share the demands of their work which were frequently perceived as burdensome. Opportunities for talking and offloading through informal peer supervision or (in)formal support from senior members of staff helped staff to develop a shared understanding. Support structures which could meet both staff's personal and professional needs were highly valued by the hospice team and desired by the community team. Though not consistently voiced, additional psychology services for families were discussed as desired forms of indirect support to clinical staff. The value of clinical supervision was discussed extensively by participants. Opportunities for group supervision were valued as a team and a helpful resource to create shared understanding and greater cohesion through the forming of trust. Accounts varied with regards to what constituted 'proper' supervision and a distinction drawn between clinical and management supervision. Many participants spoke of a desire for work to be a space which acknowledged staff as both human beings and professionals. Suggestions included protected lunch breaks and more opportunities to connect with team members, for example on away days. It was hoped that this would help staff to get to know each other better and as result increase cohesion and coping.

4.2 Addressing the Research Questions

This study was concerned with exploring the experiences of dilemmas encountered by staff working in PPC with a particular focus on the ways staff coped, made sense of and used support to help them deal with these dilemmas. This section therefore, addresses the research questions by discussing them in the context of the existing literature and psychological theory.

4.2.1 What types of dilemmas do clinical staff working in PPC experience?

The analysis revealed that dilemmas were a frequent occurrence in participants' working lives and were experienced as uncomfortable and challenging. Staff talked about their struggle to negotiate multiple perspectives and arrive at decisions. Difference of opinion amongst professionals has been shown to be not uncommon in PPC. Professional differences may be regarding a child's prognosis, treatment decisions or ethical concerns and may make collaborative working difficult (Randolph et al., 1999; Randolph, Zollo, Wigton & Yeh, 1997).

Dilemmas seemed particularly challenging when participants' decisions underpinned by professional codes or guidelines opposed the views of families and were likely to jeopardize their relationships. The notion that the close working relationship between staff and families is of critical importance but also the source of stress for staff has been echoed in the literature (Clarke et al., 2007). Examples of dilemmas discussed by participants around whether or not to raise concerns about inadequate or unsafe caring or feeding practices by parents are consistent with research on staff stress in PPC. A study by McCloskey et al. (2010) highlighted that staff had to confront complex ethical dilemmas when they encountered parents who were reluctant to follow professional advice around treatment options such as the provision of equipment or withdrawal of treatment, whilst trying to act in the best interest of the child. Such dilemmas presented a great source of stress for staff.

The above study also highlighted the pressures created by the unpredictability of the work and responsibility of making key decisions in crisis situations or when working alone. These challenges were reflected in this study where dilemmas

were exacerbated by the unexpected nature of a situation. Dilemmas seemed particularly difficult to negotiate when staff were confronted by multiple opposing opinions making it difficult to retain perspective and objectivity. The challenge of negotiating multiple perspectives in PPC has been highlighted in the literature. Klein (2009) suggested that differences in opinion may hinder end-of-life decision making and give rise to moral distress in PPC nurses. This was particularly evident when staff had a close attachment to the child or were concerned about the child's potential suffering due to life prolonging treatment (Klein, 2009). Moral distress has also been shown to result from the dilemma of nurses' obligation to follow treatment orders and their duty to provide a comfortable death (Davies et al., 1996).

Whilst some dilemmas led participants to question their professional identity with regards to making the right decisions, other staff worried about acting within the limits of their professional competence for example when asked to provide training by outside professionals. A lack of clarity about one's role or acknowledgement of specialist skills by other health professionals referred to as role ambiguity in the literature, has been shown to be a source of stress for PPC community hospice and hospice nurses (McCloskey et al, 2007).

One participant spoke of the dilemmas arising in the context of limited resources and different ideas about the length of involvement with families, particularly with regards to family support beyond a child's death. Similar concerns were expressed by staff providing a PPC service in Ireland (Clarke et al., 2007). Staff feared that parents had to confront both the loss of their child and of professional relationships and that ending required careful negotiation especially after long-term involvement with services.

4.2.2 How do staff cope and make sense of these dilemmas? Which held beliefs, values or frameworks do staff draw on in order to help them make sense of the dilemmas encountered in their work?

Participants' accounts illustrated that staff working in PPC developed a greater perspective in life as a result of their unique working experiences and their

heightened awareness of death. This led them to a greater appreciation of their own lives, a process that has been mirrored in the research literature. Working with dying children has been shown to put clinical staff in touch with their own mortality which in turn highlights their priorities and can lead to opportunities for profound change and personal growth (Frankl, 1984; Powaski, 2006; Maunder, 2006). Participants also spoke of their heightened awareness of what was most meaningful in their work with families such as the engagement in often ordinary yet special activities with children and an emphasis on 'being not doing' with families. This has been echoed in a study by Olson et al. (1998). Paediatric oncology nurses were shown to manage the suffering of families and reap long-term benefits by reflecting on the most meaningful aspects of their role such as the emotional closeness or pleasure experienced in contact with families or making a positive difference in their care. Beneficial short-and long-term consequences resulted in nurses becoming less judgmental; an increase in empathy reflected in their care giving behaviours, and changes in perspective such as a greater acceptance of their limitations. Long-term consequences of peak experiences included increased compassion and confidence, greater comfort in spiritual beliefs and acceptance of death as both a positive and natural life experience. Additionally, Clarke-Steffen's (1998) model of work-related meaning-making which suggests that nurses manage to view their work with a sense of fulfillment through a dual process of giving and receiving in the context of patient care. The following four categories provided the most significant meanings: relating to others: being aware of self as nurse; experiencing life, death, and dying issues; and, experiencing diminishing qualities.

Whilst the literature provides evidence that working in PPC can be very rewarding and staff's unique position and heightened awareness sustains them in their work (Davies et al., 1996; Papadatou et al., 2001; Rushton, 2005), it has also been shown to cause conflict (Wooley et al., 1989). The struggle to resist a tendency to diminish the importance of their own personal struggle and consider their live event as ordinary in comparison to the significantly greater life-death experience encountered at work was apparent both in this study and the literature. Balancing work and home life in the face of serious life-death experiences in a hospice setting makes it difficult for staff to stop thinking about work at the end of the day

and to view ordinary events in their personal life as valuable and meaningful (Wooley et al., 1989; McCloskey et al., 2011).

In an attempt to cope with the dilemmas experienced in their work frequently moved between their professional and personal identity which often became blurred. The literature on grief distress provides some valuable insights on this. Grief distress has been found to occur in PPC nurses when they are torn between their need to express their sadness in the face of the inevitability of a child's death and adhering to professional codes of conduct, which prescribed an expectation to not cry, be cheerful and strong for the patient, and to not let emotions interfere with their work. Nurses tended to manage better if they were able to acknowledge their distress through conversations with colleagues or had opportunities to express their emotions even if not immediately and in the presence of the family (Davies et al., 1996).

Participants' accounts also illustrated that staff attempted to cope with the dilemmas of their work by focusing on the professional task in hand and separate from the emotional responses evoked in them. Psychoanalytic theory has suggested that working environments such as PPC create proximity to suffering and that life-death events induce high levels of anxiety evoked by powerful conflicting feelings and unconscious phantasies. Attempts to deny and create distance from these unwanted feelings have been observed to result in an overemphasis on procedure and task performance by nurses. However, the move away from personal contact and closeness to patients is likely to result in job dissatisfaction, low staff moral and burn-out (Menzies Lyth, 1960).

When it came to having to confront and trying to resolve dilemmas, participants frequently drew on their professional code, conduct or duty of care towards children as a means of helping them to make decisions with regards to how to proceed. Research highlights that decision-making and reaching a consensus between all professionals involved in the care of a child and families can be a challenging task (Campbell & Fleischman, 2001). It is suggested that this is due to the value-laden nature of the work and associated emotions and consequences. A review of the literature on decision-making in the care of

neonates (Campbell et al., 2001) highlights that whilst clinicians are aware of the crucial role of parents in reaching the optimal outcome for children, they remain obligated to advocate for the child's best interest. This means that clinicians' decision-making will be determined by what they think is best for the child, particularly in situations where children may be at significant risk as a result of parents' unwillingness or refusal to follow treatment regimens (Fleischman et al., 1994).

Participants' accounts revealed that they also drew on their personal identity, values and held beliefs to help them cope and make sense of dilemmas. A few participants talked about spirituality or faith as enabling them to cope in difficult situations. An awareness that life was finite and a perceived duty to make the most of opportunities helped one staff member to cope with the dilemma of doing her best in the context of limited resources. Adopting a religious philosophy seemed to help other staff to remain focused on the importance of the relationship with families and to arrive at stage of acceptance when confronted with challenging attitudes or behaviour by parents. There is a dearth of literature on the influence of faith or religion on clinicians' ability to cope with the demands of PPC. Bergin, Payne and Richards (1996) suggested that standards laid out in professional guidelines tend to approve certain values compared to others which creates a likely culture clash for both religious service users and professionals in certain service contexts (as cited in Baker & Wang, 2004). It is likely that staff consider an expression of faith or religious beliefs as inappropriate in the context of that what is expected of them as professionals but this requires further investigation by future research.

Accepting the inevitability of death has been shown to be a coping strategy adopted by nurses although it was unclear where this stemmed from (Davies et al., 1996). The attribution of meaning to a child's death seemed to be a mediating factor in the grieving process of nurses in PPC. Death as a result of fate, part of the life cycle or the will of a higher force were amongst some of the explanatory frameworks staff drew on which may have been influenced by spiritual or religious beliefs. When nurses struggled to find meaning in a child's death they commonly attributed meaning to their personal contribution of care and support to

the child and a knowledge that they had done their utmost to support the child and alleviate suffering (Neimeyer, 2001). In a cross-cultural study by Papadatou et al. (2001) differences in meaning making of childhood death were evident between Greek and Chinese nurses. Death was attributed to mostly religious forces by the majority of nurses but differences between the two ethnic groups were observed in terms of their response to death. Greek nurses greater anger and frustration was associated with their Christian faith which perceives suffering as unjust; Chinese nurses experienced a greater sense of relief associated with their Eastern religious beliefs where death is constructed as salvation from suffering.

Participants' efforts to draw on aspects of both their professional and personal identity only aided coping to a certain extent. Staff talked about their need to employ self-caring strategies to manage the perceived proximity with families and create both a physical and emotional distance. The literature illustrates that nurses in PPC appear to frequently absorb the stress of families and consequently experience anxiety which often spills into their personal lives (McCloskey et al., 2010). Psychoanalytic theory helps to make sense of staff's need to distance themselves from their work. Working with death and dying, staff are painfully reminded of their mortality and may identify with past losses thus leading them to employ conscious or unconscious coping strategies such as avoidance, task-centeredness or chronic niceness (Speck, 1994).

The 'emotional load' of PPC is referred to in the literature as is staff's need to take regular breaks to help them cope with the demands of their work. Staff in PPC tend to form very close attachments with families which they experience as critical within their role (Clarke et al., 2007; McCloskey et al., 2010). Benner (2001) highlighted the intimacy as a unique feature of the nurse-patient relationship, particularly in PPC where nurses witness poignant moments through the provision of end-of-life care. Participants frequently showed aspects of their personal identity for the purpose of engagement and relationship building whilst needing to create or retain a distance. This appeared to be a conscious strategy employed for the purpose of engagement with families. This is echoed in Carter's (2000) theme of 'entering the tapestry' which implies that the delivery of

meaningful care is only possible in the context of a trusting relationship between staff and family (Maunder, 2006). Staff's struggle to take their mind off work as a result of their unique experiences and need to have recreational time outside of the workplace has also been highlighted (McCloskey et al., 2010; Stedeford, 1984). Practical strategies to help participants 'switch off' from work such as regular breaks, leisure or social activities mapped onto those found in the literature (Maytum et al., 2004).

4.2.3 What actual or desired systems of support do staff have to help them cope?

Participants' accounts illustrate that they valued and used a range of support systems which helped them cope with dilemmas at work. Although support varied slightly in formality and structure across the two settings, informal peer support was consistently perceived to be the most valuable source of support. This is echoed in the literature which indicates peer support provides opportunities for sharing with colleagues thus significantly lowering stress levels (Barnes, 2001; Landsdown, Pike & Smith, 1990) as well as creating a shared understanding (Woolley et al, 1989). This fits with the experience of participants who perceived 'offloading' as beneficial for coping with and sharing the demands of the work frequently referred to as a 'burden'.

Participants also referred to the comfort and encouragement gained from having supportive colleagues and the value of a supportive working environment especially when working predominantly on their own. Peer support has been shown to alleviate isolation and that having a home-like atmosphere in the working environment decreases stress in PPC staff (Weisman, 1981; Woolley et al., 1989). As previously discussed working with death and dying evokes anxiety and conflict; staff therefore require a work environment and management that is supportive and facilitates a holding environment which remedies suffering and anxiety experienced by PPC staff (Papadatou, 2006). Based on Winnicott's (1965) concept of a holding environment, staff's capacity to care for dying children and their families is enhanced through an environment which holds and

contains their distress by facilitating reflection and rituals which help to enfranchise grief and loss (McCoyd & Walter, 2007).

Sharing dilemmas with senior members of the team and managers who were perceived as approachable and operated an 'open door policy' was highly valued by participants. The benefits of this type of formal and informal support is reflected in a study by Clarke et al. (2007) in which staff discussed the importance of good relationships with managers facilitating a supportive team culture. The importance of a caring and proactive manager who is able to make and assist with decision-making has been highlighted in the literature (Spinetta et al., 2000). Owen (2000) found that stress levels were reduced if PPC staff felt valued and recognized for their work and coping enhanced through positive feedback and encouragement.

Though not consistently voiced, some participants felt that PPC services would benefit from additional counselling or psychology provisions for family members who struggled with additional psychological trauma or unresolved past losses. Staff's awareness that meeting particular needs were beyond the remit of their role not only caused stress but were also perceived as hindering the resolution of the dilemma. Vachon and Pakes (1984) have shown that role overlap or uncertainty of one's role result in caregiver stress and may lead staff to withdraw from the relationship in question. A national survey by Edwards (2010) has shown the existence of dedicated psychological input covering chronic and palliative conditions though little uniformity or equity in its distribution across the UK (as cited in Jacobs et al., 2010).

Supervision was a highly valued support system for participants as it provided a space to 'unburden', develop a shared understanding and achieve greater cohesion amongst team members. Participants' accounts highlighted that the supervisory space was used to discuss dilemmas and helped staff to make connections with each other thus enabling mutual support beyond the supervisory space. All participants received group supervision with the community team having an external facilitator and more regular sessions though attendance was not always possible due to varying shift patterns. The importance

of an external facilitator has been highlighted by Appleby (1987) who suggested that role conflict may arise if supervision is facilitated by a senior member of staff from within the care team. Supervision has been shown to be highly valued by PPC staff though attendance is not always possible due to the aforementioned reasons (Woolley et al., 1989).

All participants received individual supervision, however there was some dissonance around what constituted 'proper' supervision suggesting that it went beyond case management and provided a space for reflection. Whilst the latter was a desired support option, it was less frequently on offer to staff. The literature acknowledges that supervision offered to PPC staff may cover management or clinical issues or a combination of both (Girling et al., 2009). Johns (2001) suggested that whilst the former emphasises risk reduction and clinical effectiveness the latter focuses on empowerment. Although there is growing evidence that clinical supervision promotes well-being in staff and enhances working practices and team working, the uptake has been shown to be sparse.

Lastly, participants' accounts highlighted a desire for more opportunities to connect with work colleagues beyond the realm of work and to get to know them better. Away days, social activities for the team as well as protected lunch breaks were hoped to create a greater sense of connectedness which in turn would increase cohesion, reduce pressure amongst team members and create an even more supportive team culture. McKee (1995) refers to the use of social activities as an informal way of creating supportive relationships within teams and reducing stress levels.

4.3 Implications and Recommendations

4.3.1 Implications for Future Research

Implications for future research have been raised by the findings of this study, both in terms of research questions and methodological considerations.

This study highlighted that staff working in PPC draw on aspects of both their personal and professional identity to help them cope and make sense of the dilemmas encountered in the work. The role of faith and personal beliefs in meaning making and coping continues to be an area that has not been widely explored in PPC. It was notable that only a few participants talked about spiritual or religious beliefs despite being asked directly whether they had drawn on personal beliefs or faith to support coping and meaning making. This is interesting given that the majority of staff categorised themselves as belonging to a faith group. Further research could investigate whether staff's reluctance to talk about beliefs or faith may be linked to professional expectations to refrain from discussing or drawing on personal beliefs in work situations.

PPC is frequently provided by multi-disciplinary teams, however this was not reflected in this sample. The majority of the participants in this study were from a nursing background, whilst one member of staff came from a youth worker and one from a therapy background. Future research would benefit from drawing on staff from other professional disciplines including medical doctors, social workers, psychologists, play workers and unqualified support staff who have also shown to play a vital role in the provision of PPC. Whilst the construct of dilemmas was perceived more negatively by nursing staff, the therapist implied that dilemmas were an intrinsic part of her role and that families' narrative spoke of dilemmas. Given that the focus on dilemmas in this study evolved from conversations with clinical psychologists who have experience of working in PPC, this implies that they did not associate the term with a negative connotation; this therefore raises questions as to whether dilemmas are constructed in various ways by different professional groups. Further exploration would not only provide useful insight into this but could also potentially decrease tension in multidisciplinary team working. Employing a discursive methodology may permit a greater exploration of the various discourses held within different professions and how these may impact on staff's ability to approach or make sense of dilemmas. Furthermore future research would benefit from a sample that includes staff from various ethnic backgrounds given that this sample was predominantly White British with the exception of one person. This would develop insight into whether staff from various cultural backgrounds may have different experiences of dilemmas or

draw on different values or beliefs to help them cope with the demands of their work. It may also be interesting to gain a perspective of parents and children's views of dilemmas given that staff frequently accounted for their views and preferred choices when trying to negotiate multiple perspectives. This implies that children and families are equally affected by dilemmas and may have unique ways of coping and making sense of these which could further enhance collaborative working and help to resolve conflicts.

In addition, the phenomenological approach adopted by this study explored participants' experiences of dilemmas, coping and sense making as well as sources of support. Though not sufficiently voiced and beyond the remit of this study there was a notion that staff found it difficult to manage widely held perceptions of PPC as a service setting and hospices as places when these were encountered with families. Hospices were often perceived as fear inducing places that should be avoided which meant that staff frequently encountered resistance or suspicion. Therefore this study could be complemented by research that employs a more critical, discursive approach such as Foucauldian discourse analysis with the aim of describing and critiquing the discourses held within society about the care for dying children and their implications for practice.

4.3.2 Implications for Clinical Practice

The study's finding confirmed that supervision was an essential support system that helped staff cope with the dilemmas of their work. Although all staff received group supervision not all staff were able to access clinical supervision or were unsure about the distinction between clinical and management supervision. The Private and Voluntary Health Care (England) Regulations (2001) prescribe supervision as a mandatory requirement for hospices. Clinical supervision has also been widely advocated and is considered an essential requirement for staff in children's hospice due to the nature of the work (NMC, 2008; DoH, 1999; 2002; 2004). Nonetheless, evidence suggests that uptake has been sparse linked to a lack of clarity of how clinical supervision is defined and negative attitudes towards the supervision process (Cottrell, 2002). East Anglia's Children's Hospices have

shown that clinical supervision can be successfully implemented with help of an expert external facilitator and 'internal champions' (Girlin et al., 2009).

The benefit of an external facilitator was highlighted in this study alongside a wish for supervision by a clinical psychologist by those staff who had previously experienced such input. The perceived advantage seemed to be linked to clinical psychologist's competence of working with both individuals and staff teams through offering consultation, supervision and reflective practice and their additional knowledge of paediatric psychology thus having greater insight into the issues arising when working with children and families (Kalus et al., 2008).

Jacobs, Titman and Edwards (2012) highlighted that the promotion of psychologists as providers of supervision, consultation and reflective practice in paediatric settings continues to be a challenge despite these roles being valued and increasing team communication and cohesion. The breadth and depth of training and experience across the life span makes clinical psychologists suitable candidates for providing group work and training for staff working in PPC. Providing training about grief and loss and as well as helping staff to develop skills for engaging with bereaved or traumatised families and children would undoubtedly enhance staff's psychological awareness and develop a greater understanding of defensive or challenging behavior by parents or children as a form of communicating their distress. Furthermore, clinical psychologists are well placed to provide group work for staff who have been shown to benefit from opportunities to process their reactions to loss and death within the context of their work. This has been shown to be of vital importance given that staff frequently experience disenfranchised grief resulting from societal expectations of continued strengths and power (Papadatou, 1997).

Lastly, clinical psychologists are also usefully placed in PPC service to provide direct interventions to children with LLCs and their families. Whilst it appears as though such service provision depends on local resources and service structures, some participants in this sample voiced the lack of this provision in their services and desired such a resource. Staff hoped that input by a psychologist would not only benefit the families and children themselves but additionally support PPC staff by reducing their felt pressure to support families in ways they felt ill

equipped to do. Clinical psychologists have the skills to support children to manage their anxieties evoked by often unfamiliar or traumatic environments and medical investigations as well as parents who may find it difficult to manage their child's anxiety. By bridging the relationship between psychological and physical health care (Jacobs et al., 2012) they can make a valuable contribution to PPC.

4.4 Critical Review

4.4.1 Quality in Qualitative Research

Principles for evaluating quality and validity in research are required to be consistent with the philosophical assumptions held and the aims which inform the research method (Fossey et al, 2002). Given the diversity of methods and epistemological positions encompassed within qualitative research, it has been challenging to develop criteria which appropriately evaluate the validity and quality across the many different approaches (Smith et al, 2009).

Elliot et al (1999) developed guidelines for best practice in qualitative research which were derived from a phenomenological–hermeneutic tradition. In an attempt to ensure good practice in the conduct of my study I followed these guidelines and also took into account Yardley's (2000) principles for assessing quality, particularly those of sensitivity to context and transparency and coherence.

A further consideration of mine has been to acknowledge that as a researcher I become the co-creator of knowledge that is represented in participants' accounts and that qualitative research is therefore *'not an objective rendering of reality but a form of participation in the phenomena under study'* (Russell & Bohan, 1999; p.404). I have therefore sought to address issues of reflexivity throughout this study.

Owning One's Perspective

In chapter 2 I described my theoretical orientation and also discussed personal influences which are pertinent to and are likely to have impacted on my

understanding of the phenomenon under investigation. These include my status as and experiences of being a trainee clinical psychologist as well family values, beliefs and personal experiences with regards to death and dying. In a later section (4.6 Personal Reflections) I also endeavour to make explicit how these became apparent throughout the research process and discuss my use of a reflexive journal as a way of recording and reflecting on my thoughts about the interaction of my held values and assumptions and the research.

Situating the Sample

I attempted to contextualise the data by providing details about the service settings where participants were recruited from (see chapter 2) and including basic demographic details of the participants (see Table 1, chapter 3). The aim of my descriptions was to allow the reader to relate the findings to a range of other people and situations (Mays & Pope, 2000).

Grounding in Examples

In chapter 3 of this write-up I endeavoured to be transparent about both the analytic process and the way in which I arrived at my understanding of the participants' experiences by including both direct quotations alongside synthesised descriptions of participants' accounts. I hope that this will bring readers as close as possible to the experiences described by the participants (Popay, Rogers & Williams, 1998).

Credibility Checks

Barker, Pistrang and Elliott (2002) emphasise the importance of credibility checks in qualitative research. However, the value of carrying out member checks has been questioned (Smith, 2003; Webb, 2003). Taking into account suggestions that respondent validation is not compatible with the assumptions and idiographic focus of IPA, I nevertheless asked participants to comment on a written summary of the interim analysis. Whilst I considered this an important step in finalising my analysis and establishing whether my account was meaningful for the participants, I remained mindful that differences in participants' accounts would provide additional data rather than invalidate my own account (Bloor, 1997). Unfortunately, in the given time frame only one participant responded with

positive feedback suggesting that the account provided useful insights into colleagues' perspectives on dilemmas. Additionally, I took into account the findings of my supervisor's preliminary analysis of one of the transcripts and also asked one of my peers to code one of my transcripts which then allowed me to compare the congruence between codes and themes. As a novice researcher, these methods undoubtedly helped me to feel more confident that my developing analysis was credible, however, I did not treat them as means of achieving one definite account or truth which is an assumption that is incompatible with IPA (Smith et al., 2003).

Coherence

According to Yardley (2000) coherence in qualitative research is achieved through a careful analysis and write-up which allows the reader to follow the steps taken during data collection and analysis and attends to both convergence and divergence within participants' accounts. Through my discussion and the use of a visual display of the hierarchical relationship between super- and sub-ordinate themes (Table 1, chapter 3), I hoped to be transparent and explicit about the process of arriving at my interpretations; in addition, I sought to make further tentative inferences about the way in which themes are inter-related in the summary of my analysis (see chapter 4).

Accomplishing General vs. Specific Research Tasks

This study identified a number of ways in which staff working in PPC cope and makes sense of the dilemmas encountered in their work. As such this study provides plausible insights specific to the participants who took part in this study as opposed to definite or an exhaustive range of experiences and it therefore does not claim generalizability (van Manen, 1990). On the other hand, it is likely that these experiences are not unique to this study's sample. Willig (2001) suggests a more useful way of considering the generalisability of research through the concept of 'representativeness'. She assumes that once a given experience has been identified it is also likely to be available in other social or cultural contexts. Through my discussion of the findings in the context of the existing research literature I conclude that this study provides insights that are of

relevance beyond this group of participants to other related settings or groups of people.

Resonating with Readers

Yardley (2000) suggests that a study's validity lies in its achievement to tell the reader something that is of interest and importance. I sought to bring alive participants' experiences and preserve the integrity of their accounts by carefully selecting quotes with minimal editing and paying attention to their use of language and metaphor. I aspired to provide an engaging and stimulating read and increase the reader's understanding of the material by balancing detailed analysis of longer quotes with more general interpretations.

4.4.2 Methodological Considerations

Recruitment

As previously described, access to participants varied according to the two service settings. For the community hospice service, I was given an opportunity to meet the majority of staff members whilst presenting my study proposal during a team meeting. This meant that participants were able to meet me face-to-face, ask questions and express an interest in my study which led to a good response rate. In comparison, access to staff members working at the children's hospice was greatly filtered by the service manager who approached a number of staff directly based on whom she perceived to be more motivated to share their experiences in addition to sending out an email invitation. It is likely that participants who volunteered to discuss their experiences with me considered dilemmas more meaningful and placed particular importance on support structures as a means of coping and meaning making. However, participants' accounts demonstrated a good range of experiences suggesting that the recruitment process did not necessarily bias towards staff members who felt overly positive or negative about their working environments.

Sample

Purposive homogenous sampling is theoretically consistent with IPA's orientations of gaining insights into particular experiences which is only achievable with a selection of participants for whom the research question is meaningful (Smith et al, 2009). My sample was homogenous in that all participants worked clinically in PPC; however, a limitation was imposed by the lack of diversity within the sample with regards to ethnicity, race and religion. Whilst only two members of staff were men and therefore formed a minority within the sample this is likely to be an accurate reflection of the male to female ratio in PPC or more generally of the caring professions. Unfortunately, the sample did not contain any support staff meaning that the voices of qualified clinical staff were prioritised. This is unfortunate given the important role that support staff have shown to play in PPC (Swinney et al., 2007).

Interviews: Researcher – Participant Interaction

The research interview represents an interactive process which relies on the joining up of researcher and participant in order to develop a consensual truth. This process of interactive negotiation creates a flow of information and interpretation by both interviewer and interviewee and therefore facilitates the construction of new stories (Russell & Kelly, 2002). I was mindful of my position as a trainee clinical psychologist and how this would affect how I was perceived by the participants and ultimately affect the interview process. Whilst I was transparent about my status and highlighted the purpose of our meeting by drawing a clear distinction between a research interview as opposed to clinical supervision, I believe that my position was both conducive as well as a hindrance to engaging with participants. Some interviewees had previously received input from a clinical psychologist for supervision and consultation and had perceived this as helpful; this seemed to be reflected in the interview process which appeared to be perceived as a valuable opportunity for reflection and learning and therefore made engagement relatively easy. However, I was also mindful that participants' stories may have been skewed towards what they believed I wanted to hear. On the other hand, I felt that my position caused some anxieties amongst staff members about what to share and how they might be perceived by me which meant that I spent considerably more time on developing rapport and

creating an atmosphere where participants felt valued in sharing their knowledge and expertise. On the whole I made an effort to refrain from using psychological jargon unless the terminology had been introduced by participants and to regularly clarify and summarise participants' accounts to ensure that I had fully understood their stories.

4.5 Personal Reflections

4.5.1 Reflexivity – Coming Full Circle

Before embarking on the journey of this research study, I held quite a critical stance towards what I perceived to be a lack of opportunities for nurses to reflect on their clinical practice; as the same time I felt strongly that such opportunities were vital for staff coping and clinical psychologists had an important role to play in supporting staff. Whilst I attempted to suspend my own assumptions when interviewing staff and immersing myself in their accounts, I also remember feeling pleasantly surprised during my first interview with Sarah who talked extensively about the importance of reflection and the value she placed upon clinical supervision. As interviews progressed I also became increasingly aware of staff's need to defend against the emotional impact the work had on them, particularly in service contexts where staff were frequently pressured for time and resources and I began to doubt my belief in reflection as an essential way of coping with the demands of clinical work. Having completed this study I feel as though I have come full circle. I have recognized that staff seek opportunities for sharing and reflection as one way of coping and that clinical psychologists may be one though not the only valued resource in facilitating such support; but I have also learned to appreciate that ideally this should form part of a more holistic team culture.

4.5.2 Achieving a Balance

As a novice qualitative researcher I experienced the interview process as both engaging and enjoyable but also confusing and challenging. Trying to achieve a balance between engaging participants by drawing on my clinical skills whilst

asserting myself as a researcher as opposed to a therapist was probably what I perceived to be the greatest challenge throughout this interview process. Using a reflective journal (Appendix S) helped me to record my thoughts after each interview and reflect on the feelings that participants' accounts stirred up in me and the thoughts our encounters provoked. Noting these down enabled me to be mindful of such dynamics before entering another interview. On the other hand, I was mindful that my experience as a clinician was helpful in having a useful conversation with the participant during the debriefing process; this highlighted to me that research can be of personal and professional value to participants.

4.5.3 Final Thoughts

Having spent months engaging with the participants' accounts of their working experiences, I am reminded of the metaphor used by participants in this study. I feel as though I '[have been] on a journey' with the participants from the very moment when we first met and engaged in a conversation through to the numerous times of reading and re-reading their interview transcripts and the development and writing up of the analysis. Upon reflection on this process the following quote by Taylor (1994) resonated with me as it highlights the mixed emotions I felt when engaging in this process:

The salvaging of qualitative information is reminiscent of searching for gemstones of a certain type; some gems are of a desired type, others are precious but they are not the type being sought, and some of the other stones are clearly pieces of gravel stones and grit. (p. 187)

Whilst I experienced the research process as both enjoyable and stimulating it was also incredibly challenging and I was often plagued by a fear of getting it right and doing justice to the participants' stories. However, I recognize that qualitative analysis is not marked by a clear end point and that it can never be exhaustive and could continue to provide further insights and understandings if reanalysed again and again. Taking this into consideration I hope that this account provides what I endeavoured to achieve, that is to provide meaningful insight into the unique world of PPC through the eyes of the participants.

5 REFERENCES

- Association for Children with Life-threatening or Terminal Conditions and their Families (ACT). (2004). *A framework for the development of integrated multi-agency care pathways for children with life-threatening and life-limiting conditions*. Bristol: ACT.
- Association for Children with Life-threatening or Terminal Conditions and their Families/Royal College of Paediatrics and Child Health (ACT/RCPCH). (1997). *A guide to the development of children's palliative care services: Report of the joint working party*. Bristol: ACT/RCPCH.
- Association for Children with Life-threatening or Terminal Conditions and their Families/Royal College of Paediatrics and Child Health (ACT/RCPCH). (2003). *A guide to the development of the development of children's palliative care services* (2nd ed). Bristol: ACT/RCPCH.
- Alexander, N. & Clarke, L. (2004). You still feel different: The experience and meaning of women's self-injury in the context of a lesbian or bisexual identity. *Journal of Community and Applied Social Psychology*, 14, 70-84.
- Appleby, F.M. (1987). Professional support and the role of support groups. *Health Visit*, 60, 77-80.
- Baker, M. & Wang, M. (2004). Examining connections between values and practice in religiously committed U.K. clinical psychologists. *Journal of Psychology and Theology*, 32(2), 126-136.
- Barnes, K. (2001). Staff stress in the children's hospice: Causes, effects and coping Strategies. *International Journal of Palliative Nursing*, 7(5), 248-254.
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology: An introduction for students and practitioners* (2nd ed). Chichester: Wiley.

- Baum, J.D. (1994). Introduction: The magnitude of the problem. In A. Goldman (Ed.), *Care of the dying child* (p.43). Oxford: Oxford University Press.
- Baum, J.D., Dominica, F. & Woodward, R.N. (Eds.). (1990). *Listen my child has a lot of living to do: Caring for children with life-threatening conditions*. Oxford: Oxford University Press.
- Benner, P. (2001). *From novice to expert: Excellence and power in clinical nursing practice* (Commemorative edition). Prentice Hall, New Jersey.
- Bergin, A., Payne, I. & Richards, P. (1996). Values in psychotherapy. In E. Shafranske (Ed.), *Religion and the clinical practice of psychology* (pp. 297-325). Washington, DC: American Psychological Association.
- Bloor, M. (1997). Techniques of validation in qualitative research: A critical commentary. In G. Miller & R. Dingwall (Eds.). *Context and method in qualitative research* (pp. 37-50). London: Sage.
- Bluebond-Langer, M. (1978). *The private lives of dying children*. Princeton: Princeton University Press.
- Bosanquet, N. & Salisbury, C. (1999). *Providing a palliative care service. Towards an evidence base*. Oxford: Oxford University Press.
- Braun, E. (2007). Acknowledging staff stress and providing support. In E. Braun & B. Warr (Eds.), *Supporting the child and the family in paediatric palliative care* (pp. 242-259). London and Philadelphia: Jessica Kingsley Publishers.
- Braun, E. & Warr, B. (Eds.). (2007). *Supporting the child and the family in paediatric palliative care*. London and Philadelphia: Jessica Kingsley Publishers.
- Bush Welch, S. (2008). Can the death of a child be good? *Journal of Pediatric Nursing*, 23(2), 120-125.

- Caine, R.M. & Ter-Bagdasarian, L. (2003). Early identification and management of critical incident stress. *Critical Care Nurse*, 23(1), 59-65.
- Campbell, D.E. & Fleischman, A.R. (2001). Limits of viability: dilemmas, decisions and decision makers. *American Journal of Perinatology*, 18(3):117-28.
- Children's Hospices UK. (2004). *Are we getting it right? – A tool to measure the quality of children's hospice services*. Bristol: Association of Children's Hospices.
- Child and Maternal Health Observatory (CHIMAT) and Children's Hospices UK (2011). *Children's hospice provision 2009/10: Children's services mapping with children's hospices UK*. Durham: University School of Applied Social Sciences.
- Clarke, J. & Quin, S. (2007). Professional carers' experiences of providing a pediatric palliative care service in Ireland. *Qualitative Health Research*, 17(9), 1219-1231.
- Clarke-Steffen, L. (1998). The meaning of peak and nadir experiences of pediatric oncology nurses: Secondary analysis. *Journal of Pediatric Oncology Nursing*, 15(1), 25-33.
- Claxton-Oldfield, S., Claxton-Oldfield, J. & Rishchynski, G. (2004). Understanding the term 'palliative care': A Canadian Survey. *American Journal of Hospice and Palliative Medicine*, 21(2), 105-110.
- Contro, N.A., Larson, J., Scofield, S., Sourkes, B. & Cohen, H.J. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*, 114(5), 1248-1252.
- Cottrell, S. (2002). Suspicion, resistance, tokenism and mutiny: problematic dynamics relevant to the implementation of clinical supervision in nursing. *Journal of Psychiatric and Mental Health Nursing*, 9(6), 667-671.

- Cottrell, S., Edwards, F., Harrop, E., Lapwood, S., McNamara-Goodger, K. & Thompson, A. (2011). *A care pathway to support extubation within a children's palliative care framework*. Bristol: ACT
- Cornish, J., While, A. & Citrone, C. (1996). The contribution of voluntary organizations to the care of children with life-limiting incurable disorders and their families. *Children & Society*, 10(4), 280-292.
- Craft, A. & Killen, S. (2007). *Palliative care services for children and young people in England. An independent review for the secretary of state for health*. London: Department of Health.
- Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J., O'Loane, M. & Stutzer, C. (1996). Caring for dying children: Nurses' experiences. *Pediatric Nursing*, 22(6), 500-507.
- Davies, B. & Eng, B. (1993). Factors influencing nursing care for children who are terminally ill: A selective review. *Pediatric Nursing*, 19(1), 9-14.
- Deeley, L., Stallard, P., Lewis, M. & Lenton, S. (1998). Palliative care services for children must adopt a family centered approach. *British Medical Journal*, 317(7153), 284.
- De Graves, S. & Aranda, S. (2005). When a child cannot be cured – Reflections of health professionals. *European Journal of Cancer Care*, 14, 132-140.
- Denzin, N.K. & Lincoln, Y.S. (Eds.) (2005). *The SAGE handbook of qualitative research* (3rd ed.). Thousand Oaks, California: Sage Publications Ltd.
- Department for Education and Skills (DfES). (2004). *Every child matters: Change for children*. London: The Stationary Office.

- Department of Health (DoH). (1999). Making a difference: Strengthening the nursing, midwifery and health visiting contribution to health and healthcare. Retrieved from:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007977
- Department of Health (DoH). (2002). Liberating the talents: Helping primary care trusts and nurses to deliver the NHS Plan. Retrieved from:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007473
- Department of Health (DoH). (2004) Standards for better health. Retrieved from:
www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4086665
- Department of Health (DoH). (2005). Commissioning children's and young people's palliative care services. London: HMSO.
- Department of Health (DoH). (2007). Palliative care services for children and young people in England. London: HMSO.
- Doherty, E. (2009). *Say what – Consultation with siblings of children and young people with life-limiting conditions*. Northern Ireland Children's Hospice.
- Doka, K.J. (Ed.). (2002). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA: Lexington
- Dominica, F. (1990). Hospices: A philosophy of care. In J.D. Baum, F. Dominica & R.N. Woodward (Eds.), *Listen my child has a lot of living to do: Caring for children with life-threatening conditions* (pp. 3-5). Oxford: Oxford University Press.
- Edwards, M. (2010). *Directory of paediatric services across the UK, 2009-2010*. Unpublished survey.

- Eiser, C. (1990). *Chronic childhood disease: An introduction to psychological theory and research*. Cambridge: Cambridge University Press.
- Eiser, C. (1996). Helping the child with chronic disease: Themes and directions. *Clinical Child Psychology and Psychiatry*, 1, 551-561.
- Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Field, M.J. & Behrmann, R.E. (Eds.). (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington: The National Academies Press.
- Fleischman AR, Nolan K, Dubler NN, Epstein, M.F., Gerben, M.A., Jellinek, M.S., . . . Vaughan, V.C. (1994). Caring for gravely ill children. *Pediatrics*, 94(4), 433–439.
- Fossey, E., Harvey, C., McDermott, F. & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36, 717-732.
- Frankl, V.E. (1984). *Man's search for meaning*. New York: Washington Square Press.
- Girling, A., Leese, C. & Maynard, N. (2009). How clinical supervision can improve hospice care for children. *Nursing Management*, 16(7), 22-23.
- Goldman, A. (Ed.). (1994). *Care of the dying child*. Oxford: Oxford University Press.
- Goldman, A. & Heller, K.S. (2000). Integrating palliative and curative approaches in the care of children with life-threatening illnesses. *Journal of Palliative Medicine*, 3(3), 353-359.

- Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Hain, R.D.W. (2002). The view from a bridge. *European Journal of Palliative Care*. 9, 75-77.
- Hain, R. & Jassal, S.S. (2010). *Paediatric palliative medicine*. Oxford: Oxford University Press.
- Harper, D. (2008). Clinical psychology. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 430-454). London: SAGE Publications Ltd.
- Harper, D. (2012). Choosing a qualitative research method. In D. Harper & A.R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (1st ed.). (pp. 83-97). Chichester: John Wiley & Sons, Ltd.
- Harper, D. & Thompson, A.R. (Eds.). (2012). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (1st ed.). Chichester: John Wiley & Sons, Ltd.
- Hatano, Y., Yamada, M. & Fukui, K. (2011). Shades of truth: Cultural and psychological factors affecting communication in pediatric palliative care. *Journal of Pain and Symptom Management*, 41(2), 491-495.
- Havermans, T. & Eiser, C. (1994). Siblings of a child with cancer. *Child: Care, Health and Development*, 20, 309-322.
- Heggarty, H. (1994). Good beginnings. In L. Hill (Ed.), *Caring for dying children and their families*. London: Chapman and Hall.

Heller, K.S. & Solomon, M.Z. (2005). Continuity of care and caring: what matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing, 20*, 335-346.

Hill, L. (Ed.). (1994) *Caring for dying children and their families*. London: Chapman and Hall.

Hinds, P.S., Drew, D., Oakes, L.L., Fouladi, M., Spunt, S.L., Church, C. & Furman, W.L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology, 23*(36), 9146-9154.

Hinshelwood, R.D. & Skogstad, W. (Eds.) (2000). *Observing organisations*. London: Routledge.

Hodgkinson, R. & Lester, H. (2002). Stresses and coping strategies of mothers living with a child with cystic fibrosis: Implications for nursing professionals. *Journal of Advanced Nursing, 39*, 377-383.

Hochschild, A.R. (1983). *The managed heart. Commercialisation of human feeling*. California: University of California Press.

Hynson, J.L., Aroni, R., Bauld, C. & Sawyer, S.M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine, 20*, 805-811.

Hynson, J.L., Gillis, J., Collins, J.J., Irving, H. & Trethewie, S.J. (2003). The dying child: How is care different? *Medical Journal of Australia, 179*(6), 20-22.

Hynson, J.L. & Sawyer, S.M. (2001). Annotation. Paediatric palliative care: Distinctive needs and emerging issues. *Journal of Paediatric Child Health, 37*, 323-325.

Jacobs, K., Titman, P. & Edwards, M. (2012). Bridging psychological and physical health care. *The Psychologist, 25*(3), 190-193.

- Jaeger, M.E. & Rosnow, R.L. (1988). Contextualism and its implications for psychological inquiry. *British Journal of Psychology*, 79, 63-75.
- Johns, C. (2001). Depending on the intent and emphasis of the supervisor, clinical supervision can be a different experience. *Journal of Nursing Management*, 9(3), 139-145.
- Katz, S. (2002). When the child's illness is threatening: Impact on the Parents. *Pediatric Nursing*, 28, 453-463.
- Kalus, C., Beloff, H., Brennan, J., McWilliams, E., Payne, S., Royan, L. & Russell, P. (2008). *The role of psychology in end of life care. A report published by the professional practice board of the British Psychological Society*. BPS: Leicester.
- Keene, E.A., Hutton, N., Hall, B. & Rushton, C. (2010). Bereavement debriefing sessions: An intervention to support health care professionals in managing their grief after the death of a patient. *Pediatric Nursing*, 36(4), 185-189.
- Klass, D. (1986). Marriage and divorce among bereaved parents in a self-help group. *Omega*, 17, 237-249.
- Klein, S.M. (2009). Moral distress in pediatric palliative care: A case study. *Journal of Pain and Symptom Management*, 38(1), 157- 160.
- Knapp, C.A., Madden, V.L., Curtis, C.M., Sloyer, P. & Shenkman, E.A. (2010). Family support in pediatric palliative care: How are families impacted by their children's illnesses? *Journal of Palliative Medicine*, 13(4), 421-426.
- Kramer, R.F. (1981). Living with childhood cancer: Healthy siblings' perspectives. *Issues in Comprehensive Paediatric Nursing*, 5, 133-165.

- Kushnir, T., Rabin, S. & Azulai, S. (1997). A descriptive study of stress Management in a group of paediatric oncology nurses. *Cancer Nursing*, 20(6), 414-421.
- Landsdown, R., Pike, S. & Smith, M. (1990). Reducing stress in the cancer ward. *Nursing Times*, 86(38), 34-38.
- Larkin, M. & Thompson, A.R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In D. Harper & A.R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (1st ed.). (pp. 101-116). London: John Wiley & Sons, Ltd.
- Larkin, M., Watts, S. & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3, 102-120.
- Lenton, S., Stallard, K., Lewis, M., & Mastroyannopoulou, K. (2001). Prevalence and morbidity associated with non-malignant, life-threatening conditions. *Child: Care, Health and Development*, 27, 389-398.
- Liben, S. & Goldman, A. (1998). Home care for children with life threatening illness. *Journal of Palliative Care*, 14(3), 33-38.
- Liben, S., Papadatou, D. & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *Lancet*, 371, 852-864.
- Maguire, P. (1985). Barriers to psychological care of the dying. *British Medical Journal*, 291, 1711-1713.
- Maslow, A. (1970). *Religions, values, and peak Experiences*. New York: Viking Press.

- Mastroyannopoulou, K., Stallard, P., Lewis, M. & Lenton, S. (1997). The impact of childhood non-malignant life-threatening illness on parents. *Journal of Child Psychology and Psychiatry*, 38, 823-829.
- Matthews, K., Gambles, M., Ellershaw, J.E., Brook, L., Williams, M., Hodgson, A., Barber, M. (2006). Developing the Liverpool care pathway for the dying Child. *Paediatric Nursing*, 18(1), 18-21.
- Mauder, E.Z. (2006). Emotion work in the palliative nursing care of children and young people. *Paediatric Nursing*, 12(1), 27-33.
- Mays, N. & Pope, C. (2000). Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal*, 320, 50-52.
- Maytum, J.C., Heiman, M.B. & Garwick, A.W. (2004). Compassion fatigue and burnout in nurses who work with children with chronic conditions and their families. *Journal of Pediatric Health Care*, 18(4), 171-179.
- McCloskey, S. & Taggart, L. (2010). How much compassion have I left? An exploration of occupational stress among children's palliative care nurses. *International Journal of Palliative Nursing*, 16(5), 233-240.
- McCoyd, J.L. & Walter, C. (2007). A different kind of holding environment: A case study of group work with pediatric staff. *Journal of Social Work in End-of-Life & Palliative Care*, 3(3), 5-23.
- McKee, E. (1995). Staff support in hospices. *International Journal of Palliative Nursing*, 1(4), 200-205.
- Menzies Lyth (1960). Social systems as a defense against anxiety: An empirical study of the nursing service in a general hospital (a shortened version of the original). *Human Relations*, 13, 95-121.

- Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing*, 35(2), 86-90.
- Morstad Boldt, A., Yusuf, F. & Himelstein, B.P. (2006). Perceptions of the term palliative care. *Journal of Palliative Medicine*, 9(5), 1128-1136.
- National Health Service Executive (1998). *Evaluation of a pilot programme for children with life-threatening illnesses*. London: HMSO.
- Neimeyer, R.A. (Ed.). (2001). *Meaning reconstruction and loss*. Washington, D.C.: American Psychological Association.
- Nightingale, D.J. & Cromby, J. (Eds.) (1999). *Social constructionist psychology*. Buckingham: Open University Press.
- Nursing and Midwifery Council (NMC). (2008). *The code: Standards of conduct, performance and ethics for nurses and midwives*. London: NMC. Retrieved from: <http://www.nmc-uk.org/Documents/Standards/The-code-A4-20100406.pdf>.
- Obholzer, A. & Roberts, V.Z. (Eds.). *The unconscious at work: Individual and organizational stress in the human service*. London: Routledge.
- Olson, M.S., Hinds, P.S., Euell, K., Quargnenti, A., Milligan, M., Foppiano, P. & Powell, B. (1998). Peak and nadir experiences and their consequences described by pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, 15(1). 13-24.
- Owen, R. (2000). Relieving stress in palliative care staff. *Palliative Care Today*, 9(1), 4-5.
- Papadatou, D. (1997). Training health care professionals in caring for dying children and grieving families. *Death Studies*, 21(6), 575-600.
- Papadatou, D. (2000). A proposed model of health professionals' grieving response. *Omega*, 41, 59-77.

- Papadatou, D., Papazoglou, I., Bellali, T. & Petraki, D. (1999). Mutual support among nurses who provide support to dying children. *Illness, Crisis and Loss*, 7, 37-48.
- Papadatou, D., Papazoglou, I., Bellali, T. & Petraki, D. (2002). Greek nurse and physician grief as a result of caring for children dying of cancer. *Pediatric Nursing*, 28(4), 345-353.
- Papadatou, D., Martinson, I.M. & Chung, P.M. (2001). Caring for dying children: A comparative study of nurses' experiences in Greece and Hong Kong. *Cancer Nursing*, 24(50), 402-412.
- Pergert, P., Ekblad, S., Enskär, K. & Björk, O. (2007). Obstacles to transcultural caring relationships: Experiences of health care staff in paediatric oncology. *Journal of Pediatric Oncology Nursing*, 24, 314-328.
- Phares, V., Lopez, E. Fields, S. Kamboukos, D. & Duhig, A.M. (2005). Are fathers involved in pediatric psychology research and treatment. *Journal of Pediatric Psychology*, 30, 631-643.
- Pidgeon, N. & Henwood, K. (1997). Using grounded theory in psychological research. In N. Hayes (Ed.), *Doing qualitative research in psychology* (pp. 245-273). Hove: Psychology Press.
- Popay, J., Rogers, A. & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8, 341-351.
- Potter, J. & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behavior*. London: Sage.
- Private and Voluntary Health Care (England) Regulations. (2001). *Public Health, England: The Private and Voluntary Care (England) Regulations 2001 (No.*

- 3968). London: HMSO. Retrieved online:
http://www.legislation.gov.uk/ukxi/2001/3968/pdfs/ukxi_20013968_en.pdf.
- Powaski, K. M. (2006). Nursing interventions in pediatric palliative care. *Child and Adolescent Psychiatric Clinics of North America*, 15(3), 717-737.
- Rallison, L. & Moules, N.J. (2004). The unspeakable nature of pediatric palliative care: Unveiling many cloaks. *Journal of Family Nursing*, 10(3), 287-301.
- Randolph, A.G., Zollo, M.B., Egger, M.J., Guyatt, G.H., Nelson, R.M., Stidham, G.L. (1999). Variability in physician opinion on limiting pediatric life support. *Pediatrics*, 103(4), 807-8.
- Randolph, A.G., Zollo, M.B., Wigton, R.S., Yeh, T.S. (1997). Factors explaining variability among caregivers in the intent to restrict life-support interventions in a pediatric intensive care unit. *Critical Care Medicine*, 25(3), 435-9.
- Rapley, T.J. (2001). The art(fullness) of open-ended interviewing. *Qualitative Research*, 1(3), 302-323.
- Romesburg, T.L. (2007). Building a case for neonatal palliative care. *Neonatal Network*, 26(2), 111-115.
- Rushton, C.H. (2005). A framework for integrated pediatric palliative care: Being with dying. *Journal of Pediatric Nursing*, 20(5), 311-325.
- Russell, G.M. & Bohan, J.S. (1999). Hearing voices: The uses of research and the politics of change. *Psychology of Women Quarterly*, 23, 403-418.
- Russell, G.M. & Kelly, N.H. (2002). Research as interacting dialogic processes: Implications for reflexivity. *Forum: Qualitative Social Research*, 3(3), Art. 18. Retrieved from: <http://nbn-resolving.de/urn:nbn:de:0114-fqs0203181>.

- Silverman, D. (1993). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London: Sage.
- Silverman, D. (2002). *Doing qualitative analysis: A practical handbook*. London: Sage.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*, 261-271.
- Smith, J.A. (Ed.). (2003). *Qualitative psychology. A practical guide to research methods*. London: Sage.
- Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*, 39-54.
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods*. London: Sage.
- Speck, P. (1994). Working with dying people: on being good enough. In A. Obholzer & V.Z. Roberts (Eds.). *The unconscious at work: Individual and organizational stress in the human service* (pp. 94-100). London: Routledge.
- Spinetta, J.J., Jankovic, M., Arush, M.W.B., Eden, T., Epelman, C., Greenberg, M.L., . . . Masera, G. (2000). Guidelines for the recognition, prevention, and remediation of burnout in professionals participating in the care of children with cancer: Report of the SIOP working committee on psychosocial issues in pediatric oncology. *Medical and Pediatric Oncology, 35*, 122-125.

- Stallard, P., Mastroyannopoulou, K., Lewis, M. & Lenton, S. (1997). The siblings of children with life-threatening conditions. *Child and Adolescent Mental Health*, 2(1), 26-33.
- Stedford, A. (1984). *Facing death – Patients, families and professionals*. London: Heinemann Medical Books.
- Steele, R.G. (2002). Experiences of families in which a child has a prolonged terminal illness: Modifying factors. *International Journal of Palliative Nursing*, 8, 418-434.
- Stein, A. & Woolley, H. (1990). An evaluation of hospice care for children. In J.D. Baum, F. Dominica & R.N. Woodward (Eds.), *Listen my child has a lot of living to do* (pp. 66-90). Oxford: Oxford University Press.
- Stokes, J. (1994). Institutional chaos and personal stress. In A. Obholzer & V.Z. Roberts (Eds.). *The unconscious at work: Individual and organizational stress in the human service* (pp. 121-128). London: Routledge.
- St-Laurent-Gagnon, T., Carnevale, F.A. & Duval, M. (2008). Pediatric palliative care: A qualitative study of physicians' perspectives in a tertiary care university hospital. *Journal of Palliative Care*, 24(1), 26-30.
- Swinney, R., Yin, L., Lee, A., Rubin, D. & Anderson, C. (2007). The Role of support staff in pediatric palliative care: Their perceptions, training and available resources. *Journal of Palliative Care*, 23(1), 44-50.
- Taylor, B. (1994) *Being human: Ordinarity in nursing*. Melbourne: Churchill Livingstone.
- Tomlinson, D., Bartels, U., Hendershot, E., Constantin, J., Wrathall, G. & Sung, L. (2007). Challenges to participation in paediatric palliative care Rresearch: A review of the literature. *Palliative Medicine*, 21, 435-440.

- Vachon, M.L.S. & Pakes, E. (1984). Staff stress in the care of the critically ill and dying child. In H. Wass & C.A. Corr (Eds.), *Childhood and death* (pp. 151-182). New York: Hemisphere Publishing.
- Van Manen, M. (1990). *Researching lived experience: Human science for and action sensitive pedagogy*. Albany: The State University of New York.
- Voltz, R., Akabayashi, A., Reese, C., Ohi, G. & Sass, H.M. (1997). Attitudes of healthcare professionals toward clinical decisions in palliative care: A cross-cultural comparison. *Journal of Clinical Ethics*, 10(4), 309-315.
- Wallander, J.L. & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry*, 39, 29-46.
- Ware, J. & Raval, H. (2007). A qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and in retrospect. *Clinical Child Psychology and Psychiatry*, 12(4), 549-565.
- Wass, H. & Corr, C.A. (Eds.). (1984). *Childhood and death*. New York: Hemisphere Publishing
- Webb, C. (2003). Editor's note: Introduction to guidelines on reporting qualitative research. *Journal of Advanced Nursing*, 42(6): 544-5.
- Weisman, A.D. (1981). Understanding the cancer patient: The syndrome of caregivers plight. *Psychiatry*, 44, 161-168.
- Wheat, A. (2009). Palliative care – Evolution of a vision. *Medicine and Health, Rhode Island*, 92(1), 34-36.
- Willig, C. (2001). *Introducing qualitative research methods in psychology: Adventures in theory and method*. Maidenhead: Open University Press.

- Willig, C. (2008). *Introducing qualitative research methods in psychology: Adventures in theory and method* (2nd ed.). Maidenhead: Open University Press.
- Willig, C. & Stainton-Rogers, W. (Eds.) (2008). *The SAGE handbook of qualitative research in psychology*. London: SAGE Publications Ltd.
- Winnicott, D.W. (1965). *The maturational processes and the facilitating environment: Studies in the theory of emotional development*. Oxford: International Press.
- Woods, P. (1986). *Ethnography in educational research*. New York: Routledge & Kegan Paul Inc.
- Woolley, H., Stein, A., Forrest, G.C. & Baum, J.D. (1989). Staff stress and job satisfaction at a children's hospice. *Archives of Disease in Childhood*, 64, 114-118.
- World Health Organization (2007). *Cancer pain relief and palliative care in children*. Geneva: WHO.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228.
- Young, B., Dixon-Woods, M., Windridge, K.C., Heney, D. (2003). Managing communication with young people who have a potentially life-threatening chronic illness: Qualitative study of patients and parents. *British Medical Journal*, 326, 305-309.

6 APPENDICES

Appendix A: Literature Search Criteria

The following search engines were used to carry out a literature search for this thesis :

- PsycARTICLES
- PsycINFO
- CINAHL Plus
- Medline
- BioMed Central
- ScienceDirect
- Web of Knowledge

Searches were not restricted by a specified time period and included the following key search terms in various combinations:

- (Paediatric) palliative care
- (Children's) hospice care
- Dying children
- Staff (experiences)
- Nursing (experiences)
- Dilemmas
- Challenges
- Conflict
- Stress (responses)
- Burn out
- Decision-making
- Meaning making
- Coping (strategies/mechanisms)
- Personal and/or professional growth
- Support (systems/structures)
- Supervision/reflective practice/(staff) training
- (clinical) psychology
- Belief (systems)
- Faith
- Spirituality

The above listed search terms were also used to carry out scanning searches of Google Scholar, the British Library Catalogue and EThOS. Additionally, cascading searches were carried through reference lists of relevant journal articles, books and book chapters as well as policy documents.

Appendix B: Registration Document



Elisabeth Rothaug
[Address]
[Address]
[Address]

19 April 2011

Student Number: 0306883

Dear Elisabeth,

Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

Title of Professional Doctorate: Professional Doctorate in Clinical Psychology

Director of Studies: Dr Neil Rees

Supervisor/s: Dr Maria Castro

Expected completion: According to your actual date of registration, which is **1 October 2010**, the registration period is as follows:

Minimum 18 months, maximum 48 months (4 years), according to a full time mode of study.

Your thesis is therefore due to be submitted between:

1 April 2012 and 1 October 2014
--

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

A handwritten signature in black ink that reads 'James J Walsh'.

Dr James J Walsh
School Research Degrees Leader
Direct line: 020 8223 4471
Email: j.j.walsh@uel.ac.uk

Cc: Dr Neil Rees

Appendix C: UEL Ethical Approval

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.
uel.ac.uk/psychology



Doctoral Degree in Clinical Psychology Direct Fax: 0208 223 4967

June 2011

Name of Student	Elisabeth Rothaug
Title of Research Project	An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care

To Whom It May Concern:

This is to confirm that the above named student is conducting research as part of the requirements for the Professional Doctorate in Clinical Psychology. The Ethics Committee of the School of Psychology, University of East London has approved their proposal and they are, therefore, covered by the University's indemnity insurance policy. This policy should normally cover for any untoward event provided that the experimental programme has been approved by the Ethics Committee prior to its commencement. The University does not offer "no fault" cover, so in the event of untoward event leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the above named is a student of UEL the University will act as the sponsor of their research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Kenneth Gannon PhD
Research Director

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Appendix D: Invitation Letter – Children’s Hospice



Professional Doctorate in Clinical Psychology INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Dear [Name of Service] Staff Member,

You are invited to take part in a research study entitled ‘*An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care*’ which aims to explore your experiences of working in a paediatric palliative care setting.

Who are the researchers?

My name is Elisabeth Rothaug. I am a Trainee Clinical Psychologist and conducting this study as part of my Doctoral Training in Clinical Psychology. I am supervised by Dr Neil Rees who is a Consultant Clinical Psychologist and Clinical Director of the Doctoral Programme in Clinical Psychology at the University of East London. [Deleted text]. The research project has been registered and granted ethical approval by the University of East London and [Name of Hospice].

What is the purpose of the study?

Paediatric palliative care is an area of complexity in that it can be immensely rewarding as well as placing heavy and stressful demands upon staff. Not surprisingly, the literature and anecdotal evidence from clinicians indicate that working in this area poses many dilemmas for staff. However, to date, little research has explored the dilemmas of staff working in paediatric palliative care and therefore this study will contribute to the knowledge base informing the practice of paediatric palliative care.

Who can take part in the study?

Clinical care staff, aged 18 years and above, who have worked at [Name of Hospice] for a minimum of three months to ensure they are sufficiently familiar with the service context; this includes unqualified care staff such as support workers or nursing assistants.

What happens next if I decide to take part in this study?

I will arrange a suitable time to meet with you at [Name of Hospice]. You will be given an information sheet, consent form and have an opportunity to ask any questions. I will then conduct an interview with you which will take place in a private space at [Name of Hospice] and usually lasts between 50-75 minutes. The interview will be your chance to tell me what you would like to tell me about your experiences and about the ideas and beliefs that shape your practice. I am also interested in hearing about the ways you seek or make use of support in order to manage the demands of your work.

Will my contributions be confidential? Yes, interviews will be recorded and confidentiality maintained.

How will I benefit from taking part in this study?

Participating in this study will provide you with a valuable opportunity to:

- reflect on your practice and share your thoughts, experiences, knowledge and skills
- contribute to the knowledge base that informs paediatric palliative care

- and to make your views heard, thus shaping and influencing ways of working at [Name of Hospice]

How do I get involved?

If you are interested and/or would like to ask further questions before making a decision please contact me on via email [email address] or by phone [mobile number]. Alternatively, you can inform [Name of Service Manager] who will then put you in touch with me.

Thank you very much for taking the time to read this information, I look forward to hearing from you.

Elisabeth Rothaug

Trainee Clinical Psychologist, University of East London

Appendix E: Updated Invitation Letter - Children's Hospice



Professional Doctorate in Clinical Psychology INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Dear [Name of Service] Staff Member,

I am looking for clinical members of staff to take part in a research study entitled '*An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care*' which aims to explore your experiences of working in a paediatric palliative care setting. You are invited to meet with me for an interview at [Name of Hospice], which will be your chance to tell me about your experiences and about the ideas and beliefs that shape your practice.

A number of staff members at [Name of Hospice] have already participated. Read below what some of them thought about their interview experience:

'I participated in the Clinical Psychology research being carried out by Elisabeth Rothaug. I found this very enlightening and a great reflective tool to difficult cases in the previous few months. I would recommend this to all of the staff at [the hospice], as I feel everyone would get something from it. I did feel apprehensive at first, but the session is very relaxed and is run at one's own pace. It is geared towards your own experiences and I came away with a much clearer picture of the role I played in caring for children in [the hospice]. Please give your time to this worthy research and let's help highlight the struggles we face and promote the excellent work we do.'

[Name of Participant]

'In terms of my interview, this went really well and I found it to be quite interesting. I thoroughly enjoyed speaking about my experiences at the Hospice as it allowed me to reflect on the work we do here at [the hospice]. I think it is really important we all comment on our experiences as this will enable others to get a better understanding of our working environment in palliative care. Benefits of this are that I personally felt self satisfaction by helping someone in their work as well as contributed towards a great piece of research. I'd definitely recommend this to others to take part in. Don't miss out on this opportunity guys!'

[Name of Participant]

If you are interested and/or would like to ask further questions before making a decision please contact me on via email [email address] or by phone [mobile number]. Alternatively, you can inform [Name of Service Manager] who will then put you in touch with me. Pleas find attached further information about my study.

Who are the researchers?

My name is Elisabeth Rothaug. I am a Trainee Clinical Psychologist and conducting this study as part of my Doctoral Training in Clinical Psychology. I am supervised by Dr Neil Rees who is a Consultant Clinical Psychologist and Clinical Director of the Doctoral Programme in Clinical Psychology at the University of East London. [Deleted text]. The research project has been registered and granted ethical approval by the University of East London and [Name of Hospice].

What is the purpose of the study?

Paediatric palliative care is an area of complexity in that it can be immensely rewarding as well as placing heavy and stressful demands upon staff. Not surprisingly, the literature and anecdotal evidence from clinicians indicate that working in this area poses many dilemmas for staff. However, to date, little research has explored the dilemmas of staff working in paediatric palliative care and therefore this study will contribute to the knowledge base informing the practice of paediatric palliative care.

Who can take part in the study?

Clinical care staff, aged 18 years and above, who have worked at [Name of Hospice] for a minimum of three months to ensure they are sufficiently familiar with the service context; this includes unqualified care staff such as support workers or nursing assistants.

What happens next if I decide to take part in this study?

I will arrange a suitable time to meet with you at [Name of Hospice]. You will be given an information sheet, consent form and have an opportunity to ask any questions. I will then conduct an interview with you which will take place in a private space at [Name of Hospice] and usually lasts between 50-75 minutes. The interview will be your chance to tell me what you would like to tell me about your experiences and about the ideas and beliefs that shape your practice. I am also interested in hearing about the ways you seek or make use of support in order to manage the demands of your work.

Will my contributions be confidential? Yes, interviews will be recorded and confidentiality maintained.

How will I benefit from taking part in this study?

Participating in this study will provide you with a valuable opportunity to:

- reflect on your practice and share your thoughts, experiences, knowledge and skills
- contribute to the knowledge base that informs paediatric palliative care
- and to make your views heard, thus shaping and influencing ways of working at [Name of Hospice]

How do I get involved?

If you are interested and/or would like to ask further questions before making a decision please contact me on via email [email address] or by phone [mobile number]. Alternatively, you can inform [Name of Service Manager] who will then put you in touch with me.

Thank you very much for taking the time to read this information, I look forward to hearing from you.

Elisabeth Rothaug
Trainee Clinical Psychologist, University of East London

Appendix F: Invitation Letter - Community Hospice Service



Professional Doctorate in Clinical Psychology INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Dear [Name of Service] Staff Member,

You are invited to take part in a research study entitled 'An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care' which aims to explore your experiences of working in a paediatric palliative care setting.

Who are the researchers?

My name is Elisabeth Rothaug. I am a Trainee Clinical Psychologist and conducting this study as part of my Doctoral Training in Clinical Psychology. I am supervised by Dr Neil Rees who is a Consultant Clinical Psychologist and Clinical Director of the Doctoral Programme in Clinical Psychology at the University of East London. [Deleted text]. The research project has been registered and granted ethical approval by the University of East London and [Name of Service].

What is the purpose of the study?

Paediatric palliative care is an area of complexity in that it can be immensely rewarding as well as placing heavy and stressful demands upon staff. Not surprisingly, the literature and anecdotal evidence from clinicians indicate that working in this area poses many dilemmas for staff. However, to date, little research has explored the dilemmas of staff working in paediatric palliative care and therefore this study will contribute to the knowledge base informing the practice of paediatric palliative care.

Who can take part in the study?

Clinical care staff, aged 18 years and above, who have worked at [Name of Service] for a minimum of three months to ensure they are sufficiently familiar with the service context; this includes unqualified care staff such as support workers or nursing assistants.

What happens next if I decide to take part in this study?

I will arrange a suitable time to meet with you at [Name of Service]. You will be given an information sheet, consent form and have an opportunity to ask any questions. I will then conduct an interview with you which will take place in a private space at [Name of Service] and usually lasts between 50-75 minutes. The interview will be your chance to tell me what you would like to tell me about your experiences and about the ideas and beliefs that shape your practice. I am also interested in hearing about the ways you seek or make use of support in order to manage the demands of your work.

Will my contributions be confidential? Yes, interviews will be recorded and confidentiality maintained.

How will I benefit from taking part in this study?

Participating in this study will provide you with a valuable opportunity to:

- reflect on your practice and share your thoughts, experiences, knowledge and skills
- contribute to the knowledge base that informs paediatric palliative care
- and to make your views heard, thus shaping and influencing ways of working

How do I get involved?

If you are interested and/or would like to ask further questions before making a decision please contact me on via email [email address] or by phone [mobile number].

Thank you very much for taking the time to read this information, I look forward to hearing from you.

Elisabeth Rothaug

Trainee Clinical Psychologist, University of East London

Appendix H: Participant Information Sheet



Professional Doctorate in Clinical Psychology INFORMATION SHEET FOR RESEARCH PARTICIPANT

You are invited to take part in a research study entitled '*An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care*' which aims to explore your experiences of working in a paediatric palliative care setting. Before you decide whether you would like to give consent to take part in this study, please take the time to read the following information which will help you understand why the research is being carried out and what it will involve.

Who are the researchers?

The study is conducted by Elisabeth Rothaug. I am Trainee Clinical Psychologist at the University of East London and I am conducting this study as part of my Doctoral Training in Clinical Psychology. The project is supervised by Dr Neil Rees who is a Consultant Clinical Psychologist and Clinical Director of the Doctoral Programme in Clinical Psychology at the University of East London. [Deleted Text]. The research project has been registered and granted ethical approval by the University of East London and [Name of Service].

What is the purpose of the study?

Paediatric palliative care is an area of complexity in that it can be immensely rewarding as well as placing heavy and stressful demands upon staff. Not surprisingly, the literature and anecdotal evidence from clinicians indicate that working in this area poses many dilemmas for staff. However, to date, little research has explored the dilemmas of staff working in paediatric palliative care and therefore this study will contribute to the knowledge base informing the practice of paediatric palliative care.

Who can take part in the study?

Clinical care staff, aged 18 years and above, who have worked at [Name of Service] for a minimum of three months to ensure they are sufficiently familiar with the service context; this includes unqualified care staff such as support workers or nursing assistants.

Do I have to take part in this study?

No, you are not obliged to take part in this study, and are free to withdraw at any time during the research process. Should you choose to withdraw from this study, you do not have to give a reason for your decision and will not experience any disadvantage as a result of your withdrawal.

What happens next if I decide to take part in this study?

I will arrange a suitable time to meet with you in a private space at [Name of Service]. You will be given an information sheet and have an opportunity to ask questions before signing a consent sheet of which you will keep a copy. I will then conduct an interview with you which usually lasts between 50-75 minutes. The interview will be your chance to tell me what you would like to tell me about your experiences and about the ideas and beliefs that shape your practice. I am also interested in hearing about the ways you seek or make use of support in order to manage the demands of your work.

Will my contributions be confidential? Yes, confidentiality and anonymity of any data collected during interviews will be assured by assigning each participant a code. Participant codes and consent forms will be kept in a locked location. Interviews will be recorded using a digital voice recorder and transcribed verbatim by the researcher. Once the transcription process has been completed, interview recordings will be erased. Information provided during interviews such as names, places or personal information, which could identify the interviewee or any other people, will be anonymised. Only the researcher, research supervisors and examiners will have access to the transcribed material. Any data collected throughout the research process, including transcripts and consent forms, will be destroyed once the examination of the research has been concluded.

What happens after I have completed the interview?

Once the interview has ended and the recording is terminated you will have an opportunity to ask me any questions. There is a small possibility that sharing your experiences of working in paediatric palliative care brings up any issues or leaves you feeling emotional or distressed. Should this be the case, you will be able to take a break or halt the interview altogether or discuss any issues with me after the interview. You will also be given a debriefing information sheet containing details of organisations which you can contact should you wish to talk to someone about any issues that arose as a result of your participation.

How will I benefit from taking part in this study?

Whilst participation in this study is voluntary and you will not be reimbursed for your time, taking part will provide you with a valuable opportunity to:

- reflect on your practice and share your thoughts, experiences, knowledge and skills
- contribute to the knowledge base that informs paediatric palliative care
- and to make your views heard, thus shaping and influencing ways of working at [Name of Service]

Has this study been granted ethical approval?

Yes, this study was approved by the University Research Ethics Committee. If you have any queries regarding the conduct of the research project in which you are being asked to participate, please contact Dr James J Walsh, School Research Degrees Leader, University of East London, Stratford Campus, London E15 4LZ (Tel: 020 8223 4472, email: j.j.walsh@uel.ac.uk).

This study was also approved by [Name of Service] and I was given permission to approach staff working at [Name of Service] as potential study participants. Please contact [Name of Service] at [Name of Service] for further information.

Thank you very much for taking the time to read through this information sheet.

**Elisabeth Rothaug
Trainee Clinical Psychologist, University of East London**

Appendix I: Consent Sheet



Professional Doctorate in Clinical Psychology PARTICIPANT CONSENT FORM

Project Title:

'An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care'

Researchers:

Principal Investigator: Elisabeth Rothaug, Trainee Clinical Psychologist, University of East London

Research Supervisor: Dr Neil Rees, Consultant Clinical Psychologist and Clinical Director of the Doctoral Programme in Clinical Psychology, University of East London

- I have read the 'Information Sheet for Participants' for the above study in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the study have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.
- I understand that my involvement in this study and particular data from this study will remain confidential. It has been explained to me that the interview will be recorded and that the information provided during the interview will be anonymised. I understand that interview recordings will be erased once the content has been transcribed and that any data collected throughout the research process will be destroyed once the examination of the research has been concluded. I am aware that only the researchers involved in this study will have access to the data.
- I understand that I have the right to withdraw from this study at any time without disadvantage to myself and without being obliged to give a reason for my withdrawal.
- I have been informed that I will have an opportunity to ask questions and will receive a debriefing information sheet after completing the interview.
- I hereby agree to take part in this study.

.....
Name of Participant

.....
Signature

.....
Date

.....
Name of Researcher

.....
Signature

.....
Date

Appendix J: Interview Guide

Revised guide for semi-structured interviews to be conducted with staff working in paediatric palliative care

Setting the scene - not recorded

- welcome and introductions
- outline rationale of the study
- reiterate confidentiality and informed consent
- explain nature of interviews such as estimated length, conversation about the interviewee's experiences, interviewee encouraged to ask questions, communicate if unsure about any question or wants question to be repeated etc.
- remind interviewee to refrain from giving names of colleagues or clients; emphasise that data will be anonymised
- emphasise that recording will only start when interviewee ready and comfortable

Interview – begin recording

1. Please tell me your name, your profession and where you work?

2. Can you tell me how you came to work in paediatric palliative care?

*Prompts: How long ago?
 What brought this about?
 Have you always wanted to work or had an interest in working in
 this field?*

3. What are all the different aspects of your role?

*Prompts: Are there any aspects of your role, which make your job
 worthwhile?
 Are there any aspects of your role, which make your job difficult?*

4. Has working in paediatric palliative care changed you on a personal and/or professional level?

*Prompts: Do you see yourself or the world differently as a result of your
 experiences?
 In what ways?*

5. I'm interested to hear about your experience of dilemmas at work. Can you tell me what your understanding of a dilemma is?

*Prompts: How would you define 'dilemma'?
Is there another word you would rather use instead of 'dilemma'?
One definition of a dilemma is 'A problem, which offers at least two possibilities neither of which feels fully satisfactory to you'.
How does this fit with your understanding of 'dilemma'*

6. Can you tell me about a time when you were faced with a dilemma at work?

*Prompts: Can you think of a time when you were faced with a situation where a number of options were available to you but none of them seemed to really fit with you?
What happened?
What was the dilemma in that?
Were you the only person that felt that this was a dilemma?
How did you feel?
How did you cope?*

If person needs further prompting, give an example of common dilemmas:

'A dilemma that commonly occurs in your line of work is around death and dying, e.g. a child you work with asks whether he or she is going to die but the child's parents have made it clear to you that they don't want their child to know that he/she is going to die'

'A dilemma that commonly occurs in your line of work is around feeding, e.g. a child you work with has lost his/her swallowing function and needs to be tube fed to prevent him/her from choking. The child's parents have been informed about this and the risk for their child if he/she is given solid foods. Food is a very important part of this family's life and they continue to bring food for the child to eat every time they visit'

*Prompts: Can you think of a time when you were faced with a situation where a number of options were available to you but none of them seemed to really fit with you?
What happened?
What was the dilemma in that?
Were you the only person that felt that this was a dilemma?
How did you feel?
How did you cope?*

7. What was it that challenged you about this particular experience/situation?

*Prompts: What would have made this experience/situation less challenging?
Has this dilemma changed how you think or feel about yourself?
How did it affect you professionally?*

*Has this experience changed the way you approach similar situations at work?
How did it affect you personally?*

8. How did you make sense of this dilemma?

*Prompts: What experiences or beliefs did you draw on that helped you to make sense of this dilemma?
E.g. religious, spiritual. cultural belief?
Ideas of being a parent or family values?
Knowledge systems or professional ideas?
Medical discourses?
Were you surprised by how you tried to make sense of what happened?*

9. What support did you have that helped you deal with the experiences/dilemmas you discussed with me?

*Prompts: work, colleagues, partner, friends?
How helpful was this support?
Was it what you wanted or needed?*

10. What support do you generally have on offer to help you cope with the pressures of work?

11. If it was up to you, say you were the manager of your place of work, what types of support systems would you put in place for your colleagues?

Prompts: supervision, reflective groups, time for coffee rounds or informal chats etc.

12. Is there anything else you would like to share, which I haven't asked you about?

13. Do you have any questions?

Thank you very much for taking the time to take part in this interview – end recording

Appendix K: Demographic Information Form

Participant Name:

Job Title:

Gender:

Age:

Name of Service:

Ethnicity:

Religion:

Years worked in PPC:.....

Do you have any children? If yes, how many:

Appendix L: Debriefing Sheet



Professional Doctorate in Clinical Psychology DEBRIEFING INFORMATION SHEET

Project Title:

'An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care'

During the interview you shared your experiences of working in a paediatric palliative care setting. You were asked to think about any dilemmas you encounter in your everyday practice and how you make sense of your experiences at work. I asked you about a range of experiences you encountered and whether these are impacted upon by your belief systems and the ways you make sense of the world. I also asked you to reflect on the ways you cope with stress, in particular ways you seek or make use of support to deal with the experiences you have at work.

The general aim of the study is to add to the current research literature relating to the experience of paediatric palliative care staff, in particular to the dilemmas encountered in their work. The specific aims are:

- To explore the types of dilemmas encountered by staff when working with parents of and children with life-limiting diagnoses
- To explore how staff cope and make sense of dilemmas encountered at work
- To elicit an understanding in how far staff's belief systems influence the meaning making process of and ways of dealing with these dilemmas
- To gain an understanding of the actual or desired systems of support which facilitate coping when encountering dilemmas at work

Sometimes talking about your experiences can stir up uncomfortable feelings. If you feel like you would like to talk to someone about any difficulties, worries or issues that arose from taking part in this interview then the below information might be of interest to you. The following organisations offer confidential support and advice and are contactable via telephone:

- ❖ The Bereavement Trust offers a free national helpline staffed by volunteers who offer a 'sympathetic listening ear' to anyone struggling with bereavement. Call the helpline for free on Tel. 0800 435 455, every evening 6-10pm www.bereavement-trust.org.uk
- ❖ The Samaritans offer a helpline staffed by volunteers who you can talk to at any time of the day or night. Calls are charged at 2p from a BT landline. Helpline Tel. 08457 90 90 90 www.Samaritans.org

Should you have any questions about this study at a later stage, you can contact me, the principal researcher, via email u0306883@uel.ac.uk, telephone 07904370013 or post:

Elisabeth Rothaug, Trainee Clinical Psychologist
Doctorate in Clinical Psychology
Stratford Campus, Water Lane, Stratford E15 4LZ

Thank you very much for taking part in this interview, your participation is much appreciated and makes this study possible.

Appendix M: Transcription Scheme

(adapted from Potter et al., 1987; Silverman, 2002)

Symbol	Example	Explanation
=	<i>P: Yeah, in work it does = I: = almost feels like something that perhaps can't be</i>	Equals sign at the end of one line and beginning of the next line indicate no gap in speech between the lines.
[pause]	<i>Hmm, [pause] or I'm worried about something, I'm concerned I'm doing the right thing.</i>	Pause of more than 1 second.
[long pause]	<i>[long pause] I mean, I think my past experiences</i>	Pause of more than 5 seconds.
CAPITAL LETTERS	<i>We're all set to go because we've agreed and then at the VERY last minute we say 'sorry, we're going to have to cancel'.</i>	Capital letters indicate some form of emphasis via pitch or amplitude.
[...]	<i>I'm specialist nurse with [...] based in [...].</i>	Indicates a deliberate omission.
[]	<i>If that happened [I] would be not carrying on alone. Or just a physical dilemma [laughs].</i>	Indicates clarificatory or supplementary information.

Appendix N: Worked Example of IPA – Participant 2

Extract from Interview 2: Sarah

	741	P:	And I suppose then, yeah [pause] it was a difficult situation because	<i>fighting or</i>
<i>opposing goals</i>	742		you do tend to feel like you're fighting with community nurses and	
<i>create conflict</i>	743		fighting is probably not the best word to use but – you know – there's,	<i>feels unc with war</i>
<i>'fighting metaphor'</i>	744		you know we need to get that child home and we can't have them at	
<i>pressure to discharge us planning</i>	745		[Name of the hospice] the hospice <u>forever</u> . Like, we're not asking for	<i>similar exp</i>
	746		him to be here <u>forever</u> but we have other kids like this child and this	
<i>pressure to provide goal care</i>	747		family, you know, and we think a little bit 'Get it <u>right</u> , get it <u>right</u> the	<i>need to get right</i>
	748		<u>first time</u> and then it'll be <u>good</u> '	
	749	I:	yeah	
<i>benefits of adequate planning for everyone</i>	750	P:	And you know all your worries will be sorted and all the family's	<i>trying to reduce worries (how & fun)</i>
	751		worries and they'll have a plan of [pause] hmm, things to do	
	752	I:	Mmh. [pause] so how did you feel in this situation?	
<i>'tug of war': pulling in different directions</i>	753	P:	Oh [sighs], it was very, it was very [pause] <u>tug of war</u>	<i>tug of war: what does it mean?</i>
<i>relating as professional vs mother</i>	754	I:	Mmh	
	755	P:	you know, hmm, cause – you know – you – I mean I suppose I	
	756		couldn't – some of the people could relate the by saying 'Well, I'm a	<i>can't relate a mother</i>
	757		mother and I would want to be at home'	
	758	I:	yeah	
	759	P:	I don't have that, I had the child	
	760	I:	yeah	
<i>professional vs parent's perspective</i>	761	P:	and go on 'You know, and I can understand you want to go home	<i>attempt to explain be under reasoning it</i>
	762		and of course you want to go home and no one is ever questioning	
	763		that you're not able to look after your own child but she is – there's a	
<i>importance of planning and adequate care provision beyond hospice</i>	764		lot of problems and there's a lot of, hmm things that we need to sort	
	765		out first before we can get her there'.	
	766	I:	yeah	
	767	P:	Hmm, and you do feel at times like [pause] you know, that, that	
<i>feeling affected by decision</i>	768		[pause] it is quite a difficult situation, you know, because you see the	<i>it's hard to witness family struggle</i>
	769		family struggling. They live [pause] and they're coming over and	
	770		they're only getting to see her for an hour and a half every day	
	771		because she's got to go back for other children, bring them to school,	
	772		collect them from school, cook dinners, you know. And it is – it does	
	773		– and she comes in and you just know that she wants to have her	
<i>needing to be professional</i>	774		home and [pause] but you <u>have to stay strong</u> and say 'I just can't let	<i>doing the she's had to do => requires a</i>
	775		you go home yet'	
	776	I:	Mmh	
<i>team working: importance of planning</i>	777	P:	<u>we</u> need to make sure that <u>this</u> , <u>this</u> and <u>this</u> is in place'	
	778	I:	Mmh	

feeling personally affected	779	P:	And I find that at times – especially in the planning meetings when she was getting so upset 'I just want to bring her home'	withdrawing consequences of her decision
	780	I:	mmh	
consequence of = guilt decision	781	I:	mmh	
	782	P:	- you do feel like you're the <u>big bad wolf</u> going 'You know, we <u>do</u> want to get her home, too. We <u>really, really do</u> '	feeling guilty wanting to be under
best interest of child vs	783	I:	Mmh.	
	784	I:	Mmh.	
duty of care professional identity	785	P:	'But we HAVE to be realistic about this. You know, we get you home, you're home for a couple of hours but if this happens you have nothing to back you up'	emphasis on duty, no choice wish to resolve situation
	786			
	787			
	788	I:	mmh	
anticipating outcomes planning ahead	789	P:	'you're going to be straight back into hospital. It's pointless. You know, you're back into the situation you were before you got here, that left you to us'	wanting to prevent repetition
	790			
	791			
	792	I:	Yeah	
	793	P:	Hmm. [pause]	
	794	I:	So it sounds like there was some guilt about	
	795	P:	Yeah, I suppose you do kind of think that – yeah, there's guilt and there's – cause you're, you feel sometimes that that you're keeping that child and that mother away from each other and what's best for her – of course, it's the bonding and keeping them together, you know, she probably won't see her first birthday – and you think every minute is precious for that family. But at the same time if she's going to spend every other day going back and forth to hospital because the support is not there and the help is not there and the family is going to break down, you know, there's other children to think about as well.	feeling responsible for what is missing due to preciousness of each minute aware of risk
guilt	796			
professional conduct vs family's needs + child's best interest	797			
impact of decision	798			
awareness of precariousness of life	799			
	800			
	801			
assessing risk / parent capacity	802			
	803			
	804			
	805	I:	Mmh, mmh	
systemic factors impact on decision making	806	P:	It's a huge big picture because it's not just – if you could just look after the child then it'd be 'Yeah, this is [pause]'	can't look at child in isolation
	807			

Appendix O: Initial and Cluster Themes – Participant 2

Initial Themes: Participant 2 Sarah

1. Passion for work, p. 1, 11; p.2, 33-2; p. 2, 34 'what I was looking for the whole time'
2. Breadth of paediatric experience, p. 1, 21-2
3. PCC spans oncology, p.2, 20-3
4. Quality of life vs cure, p. 2, 41-2; 43-44
5. creating memories, p. 2, 43-4
6. making a difference, p. 3, 48; p. 49, 1181
7. focus on wellbeing vs health, p. 3, 50
8. emphasis on 'doing things', p. 3, 53—63
9. striving for best care, p. 3, 60-2
10. many demands through nursing standards and protocols, p. 3, 63-4
11. lack of control, p. 3, 65-6 'you do get pulled to admin etc.';
12. unpredictability, p. 3, 68-9; p.4, 71-5
13. extraordinary and mundane, p. 4, 73-4
14. being dependent/constrained (circumstances/people), p. 4, 88-92; 94-6
15. spending time with children, p. 5, 100-1
16. ordinary as special, p. 5, 102-8
17. responsibility – being trusted to look after children, p. 5, 108-11; 113-7
18. professionalism, p. 6, 119-22
19. code of conduct overrides personal opinion, p. 6, 125; p. 7, 160-8 (QUOTE); p. 8, 175-6; p. 9, 205-7 structure and responsibility
20. opinions of non-nursing staff, p. 6, 126-9
21. respecting family's opinions, p. 6, 131-3
22. respecting individual and cultural differences, p. 6, 135-8
23. prioritising the child's needs, p. 6, 146-8; p. 5, 132-3
24. Accountability, p. 8. 171-3; 180-2; p. 9, 200-1 'it's going to be the shift leader'
25. nurse-led environment, p. 8, 177-8; 184-8
26. struggle to make oneself understood, p. 8, 186-7; p.6, 128-30; p. 9, 194-9; p. 9, 217-20
27. Nurse registration: responsibility & weight, p. 9. 213-5; p.10, 222-6
28. responsibility internalised but kept out of awareness, p. 10, 235-7
29. reflection as process of learning, p. 10, 239-42
30. questioning self, p. 11, 244-0; p. 34, 821-3
31. weight of responsibility, p. 11, 250-5 QUOTE
32. importance of peer support, p. 11, 262-0 'bounce of each other'
33. nurse-led service, p.12, 278-1
34. responsibility is empowering, p. 12, 282-6
35. non-NHS setting: flexibility and service development, p.12, 287-302
36. being a change agent, p.13, 313-6

37. work creates perspective, p.14, 318-9 'my real worries are relative to me'
38. relating through relative's children, p. 14, 328-31
39. perception of job as hard, p. 14, 335-8
40. separate professional and personal lives/identities, p. 14, 337 Quote; p.16,
41. feeling guilty about own worries (in relation to families'), p.15, 358-64
42. professional self impacts on personal self, p. 16, 380-3; p.20, 472 Quote
43. need to create distance from professional self, p.16, 385-7;
44. tug of war, p.17, 392-5; p. 31, 753
45. difficulty to great distance from work, p. 17, 409-10
46. heightened anxiety, p. 17, 410-8; p. 21, 492
47. need to contain one's own worries, p. 18, 421
48. heightened awareness of unpredictability of life, p. 18, 423-6
49. paranoia, p.19, 442
50. dilemma; conflict needs resolving, p. 21, 507-13
51. problem/situation vs dilemma, p. 23, 541
52. negative connotation of dilemma, p.23, 551; 562-575; p. 24, 577-8
53. dilemma provokes defensive reaction, p. 24, 580-3
54. associated with blame, p. 25, 591
55. taking into account parents' wishes, p. 25, 609-1
56. professional opinion vs family's, p. 26, 617-9
57. guidelines, p. 26, 621; p. 28, 665-8 Quote
58. best interest of child, p. 26, 623
59. decisions impacting on family, p. 26, 625-7
60. need to take a position vs guidelines, vs professional opinion, p. 26, 632-43
61. professional vs personal opinion, p. 27, 645-6
62. end of life situation most challenging, p. 27, 656-7
63. multiple perspectives: conflict, p. 27, 659-1
64. shared concern helpful, p. 28, 674-0
65. need for planning, p. 28, 682
66. learning from experience, p. 29, 712-6
67. financial constraints, p. 30, 718-22; p. 43, 1042-4; 1054-8
68. perceived injustice, p. 30, 724
69. different goals create conflict, p. 31, 741-8; p. 35, 847-0
70. relating as a professional vs mother, p. 31, 755-7; p. 32, 771-5 'you have to stay strong'/'I just can't let you go home'
71. feeling guilty, p. 32, 782-3; p. 33, 796-8; p. 35, 845
72. bigger picture vs child needs, p. 32, 806-0
73. complexity, systemic factors, p. 34, 814-8; p. 37, 894-0
74. establishing trust with families, p. 34, 819
75. opposing demands, p. 35, 853
76. need to vent, offload with nursing friends, p. 36, 865-1; p. 58, 1403
77. feeling listened to, p. 36, 873-4
78. importance of discussions (in)formally, p. 36, 875-9

79. being transparent, p. 36, 888-2
80. feeling reassured (meetings), p. 37, 903-5
81. (overcoming) people's perception of hospice, p. 38, 925-32; p. 39, 938-7; p. 40, 972-3
82. need to build trust, p. 38, 933-4
83. working with cultural differences, p. 39, 952-6
84. routine and planning, p. 39, 959-0
85. providing normality for children, p. 40, 967-1; p. 41, 987-96; ordinary yet special
86. wanting the best for child and family, p. 40, 980-2
87. precious experiences,, p. 41, 1002-3
88. external factors, p. 42, 1016-36
89. acknowledging ones limitations, p. 43, 1038 'I feel like we did quite a good job';.p. 45, 1085
90. lack of control, p. 44, 1062
91. lack of support for the whole family, p. 45, 1093
92. bureaucracy, p. 47, 1135-39
93. learning to accept one's limits, p. 47, 1144; p. 48, 1165-9; 1171 'recognizing the sort of limits' ; p. 49, 1197-20;
94. limited control, p. 48., 1158-63
95. need to be realistic, p. 48, 1174-6; p. 49, 1184-6; p. 50, 1207-9; p. 50, 1223-8
96. need for self-care, p. 48, 1189;p. 51, 1243-4 Quote
97. helper identity, p. 50, 1210-5
98. learning from mistakes, p. 50, 1217-1
99. readjusting expectations, p. 50, 1221
100. choosing one's battles, p. 51, 1230-4, p. 52, 1270 'self-preservation'
101. feeling exhausted, p. 51, 1239
102. self-care as strength vs weakness, p. 52, 1254-0 Quote
103. belief: doing good/making a difference, p.53,1282-5;p.55,1338-9
104. putting the child first, p. 53, 1295
105. respecting difference, p. 53, 1296-9
106. personal beliefs vs professional values, p. 55, 133-1
107. carer identity vs need for recognition, p. 56, 1356-0
108. influence of personal experience, p. 56, 1367
109. belief in human strength, p. 56, 1374-81
110. peer support, p. 57, 1400
111. being listened to and advice, p. 58, 1410
112. reflective writing, p. 58, 1411-0
113. reflection, p. 58, 1422
114. feeling affirmed, p. 59, 1436-41
115. checking in with others, p. 59, 1434
116. knowing yourself, p. 59, 1443-8
117. ability to seek and use support, ,p. 60, 1455-7

- 118. team leader, peers, clinical supervision, p. 60,. 1462-4
- 119. informal support, open door, p. 61, 1475-6;
- 120. helpline, p. 1480-6
- 121. feeling well supported, p. 61, 1489
- 122. qualified vs unqualified staff, p. 62, 1505-6; p. 63, 1544-7
- 123. team day/space to reflect, p. 65, p. 1592-1605
- 124. Clinical psychology for parents and children, p. 44, 1068;
p.45,1085-98

Cluster Themes: Participant 2 Sarah

A: Dilemma

- (50) dilemma; conflict needs resolving, p. 21, 507-13
- (51) problem/situation vs dilemma, p. 23, 541
- (52) negative connotation of dilemma, p.23, 551; 562-575; p. 24, 577-8
- (53) dilemma provokes defensive reaction, p. 24, 580-3
- (54) associated with blame, p. 25, 591

B: Multiple perspectives

- (55) Taking into account parents' wishes, p. 25, 609-1
- (56) Professional opinion vs family's, p. 26, 617-9
- (20) Opinions of non-nursing staff, p. 6, 126-9
- (21) Respecting family's opinions, p. 6, 131-3
- (61) Professional vs personal opinion, p. 27, 645-6
- (63) Multiple perspectives: conflict, p. 27, 659-1
- (59) Decisions impacting on family, p. 26, 625-7
- (122) qualified vs unqualified staff, p. 62, 1505-6; p. 63, 1544-7

C: Being professional

- (18) Professionalism, p. 6, 119-22
- (9) Striving for best care, p. 3, 60-2
- (8) Emphasis on 'doing things', p. 3, 53—63
- (24) Accountability, p. 8. 171-3; 180-2; p. 9, 200-1 'it's going to be the shift leader'
- (25) nurse-led environment, p. 8, 177-8; 184-8; p.12, 278-1
- (70) Relating as a professional vs mother, p. 31, 755-7; p. 32, 771-5 'you have to stay strong'/I just can't let you go home'
- (47) Need to contain one's own worries, p. 18, 421

D: Prioritising the needs of the child

- (58) Best interest of child, p. 26, 623
- (23) Prioritising the child's needs, p. 6, 146-8; p. 5, 132-3
- (104) putting the child first, p. 53, 1295

E: Professional conduct

- (84) Routine and planning, p. 39, 959-0
- (10) Nursing standards and protocols, p. 3, 63-4
- (19) Code of conduct overrides personal opinion, p. 6, 125; p. 7, 160-8 (QUOTE); p. 8, 175-6; p. 9, 205-7 structure and responsibility

(57) Guidelines, p. 26, 621; p. 28, 665-8 Quote

F: Being responsible

- (27) Nurse registration: responsibility & weight, p. 9, 213-5; p.10, 222-6
- (28) Responsibility internalised but kept out of awareness, p. 10, 235-7
- (31) Weight of responsibility, p. 11, 250-5 QUOTE
- (17) Responsibility – being trusted to look after children, p. 5, 108-11; 113-7
- (34) Responsibility is empowering, p. 12, 282-6
- (28) Responsibility internalised but kept out of awareness, p. 10, 235-7

G: Personal influence

- (108) influence of personal experience, p. 56, 1367
- (2) Breadth of paediatric experience, p. 1, 21-2
- (38) relating through relative's children, p. 14, 328-31

H: Personal Motivation

- (1) Passion for work, p. 1, 11; p.2, 33-2; p. 2, 34 'what I was looking for the whole time'
- (6) Making a difference, p. 3, 48; p. 49, 1181

I: Personal beliefs/values

- (103) belief in doing good/making a difference, p. 53, 1282-5; p. 55, 1338-9 Quote
- (109) belief in human strength, p. 56, 1374-81

G: Carer identity

- (97) helper identity, p. 50, 1210-5
- (107) carer identity vs need for recognition, p. 56, 1356-0

H: Heightened awareness

- (48) heightened awareness of unpredictability of life, p. 18, 423-6
- (49) Paranoia, p.19, 442
- (37) Work creates perspective, p.14, 318-9 'my real worries are relative to me'
- (46) Heightened anxiety, p. 17, 410-8; p. 21, 492
- (41) Feeling guilty about own worries (in relation to families'), p.15, 358-64

I: Tug of War

- (42) Professional self impacts on personal self, p. 16, 380-3; p.20, 472 Quote
- (43) Need to create distance from professional self, p.16, 385-7;
- (44) Tug of war, p.17, 392-5; p. 31, 753
- (45) Difficulty to great distance from work, p. 17, 409-10
- (60) Need to take a position vs guidelines, vs professional opinion, p. 26, 632-43
- (106) personal beliefs vs professional values, p. 55, 133-1
- (69) Different goals create conflict, p. 31, 741-8; p. 35, 847-0
- (75) Opposing demands, p. 35, 853

J: Working with families: Ordinary as special

- (5) Creating memories, p. 2, 43-4
- (13) Extraordinary and mundane, p. 4, 73-4
- (15) Spending time with children, p. 5, 100-1

- (16) Ordinary as special, p. 5, 102-8
- (85) Providing normality for children, p. 40, 967-1; p. 41, 987-96; ordinary yet special
- (87) Precious experiences,, p. 41, 1002-3

K: Building trust

- (86) Wanting the best for child and family, p. 40, 980-2
- (74) Establishing trust with families, p. 34, 819
- (82) need to build trust, p. 38, 933-4

L: Working with difference

- (105) respecting difference, p. 53, 1296-9
- (22) Respecting individual and cultural differences, p. 6, 135-8

M: Dimensions of PPC

- (3) PCC spans oncology, p.2, 20-3
- (4) Quality of life vs cure, p. 2, 41-2; 43-44
- (7) focus on wellbeing vs health, p. 3, 50

N: Feeling supported

- (121) feeling well supported, p. 61, 1489
- (76) need to vent, offload with nursing friends, p. 36, 865-1; p. 58, 1403
- (77) Feeling listened to, p. 36, 873-4
- (78) Importance of discussions (in)formally, p. 36, 875-9
- (79) Being transparent, p. 36, 888-2
- (80) Feeling reassured (meetings), p. 37, 903-5
- (123) team day/space to reflect, p. 65, p. 1592-1605
- (111) being listened to and advice, p. 58, 1410
- (113) reflection, p. 58, 1422
- (114) feeling affirmed, p. 59, 1436-41
- (115) checking in with others, p. 59, 1434
- (64) Shared concern helpful, p. 28, 674-0

O: Support structures

- (120) helpline, p. 1480-6
- (110) peer support, p. 57, 1400
- (32) Importance of peer support, p. 11, 262-0 'bounce of each other'
- (118) team leader, peers, clinical supervision, p. 60,. 1462-4
- (119) informal support, open door, p. 61, 1475-6;
- (124) Clinical psychology for parents and children, p. 44, 1068; p.45,1085-98

P: Self-care

- (116) knowing yourself, p. 59, 1443-8
- (117) ability to seek and use support, ,p. 60, 1455-7
- (112) reflective writing, p. 58, 1411-0
- (102) self-care as strength vs weakness, p. 52, 1254-0 Quote
- (93) Learning to accept one's limits, p. 47, 1144; p. 48, 1165-9; 1171 'recognizign the sort of limits' ; p. 49, 1197-20;
- (96) need for self-care, p. 48, 1189;p. 51, 1243-4 Quote
- (40) Separate professional and personal lives/identities, p. 14, 337 Quote; p.16,

Q: Learning from experience

- (66) Learning from experience, p. 29, 712-6
- (29) Reflection as process of learning, p. 10, 239-42
- (30) Questioning self, p. 11, 244-0; p. 34, 821-3
- (95) Need to be realistic, p. 48, 1174-6; p. 49, 1184-6; p. 50, 1207-9; p. 50, 1223-8
- (98) Learning from mistakes, p. 50, 1217-1
- (99) Readjusting expectations, p. 50, 1221
- (100) choosing one's battles, p. 51, 1230-4, p. 52, 1270 'self-preservation'
- (89) Acknowledging ones limitations, p. 43, 1038 'I feel like we did quite a good job'; p. 45, 1085

R: Constraints

- (14) being dependent/constrained (circumstances/people), p. 4, 88-92; 94-6
- (88) external factors, p. 42, 1016-36
- (92) bureaucracy, p. 47, 1135-39
- (91) lack of support for the whole family, p. 45, 1093
- (72) bigger picture vs child needs, p. 32, 806-0
- (73) complexity, systemic factors, p. 34, 814-8; p. 37, 894-0
- (67) financial constraints, p. 30, 718-22; p. 43, 1042-4; 1054-8

S: Lack of control

- (90) lack of control, p. 44, 1062
- (94) limited control, p. 48., 1158-63
- (11) lack of control, p. 3, 65-6 'you do get pulled to admin etc.';
- (12) unpredictability, p. 3, 68-9; p.4, 71-5

T: Impact

- (68) perceived injustice, p. 30, 724
- (71) feeling guilty, p. 32, 782-3; p. 33, 796-8; p. 35, 845
- (101) feeling exhausted, p. 51, 1239
- (62) end of life situation most challenging, p. 27, 656-7

U: Perception

- (26) Struggle to make oneself understood, p. 8, 186-7; p.6, 128-30; p. 9, 194-9; p. 9, 217-20
- (39) Perception of job as hard, p. 14, 335-8
- (81) (overcoming) people's perception of hospice, p. 38, 925-32; p. 39, 938-7; p. 40, 972-3

Appendix P: Interim Analysis – Themes with Notes

INTERIM ANALYSIS

DILEMMAS – A DAILY OCCURRENCE

Negative Connotation

Participants were very familiar with the construct of ‘dilemma’ suggesting that dilemmas were a daily occurrence in their working lives. The majority of staff perceived the term to be carrying a negative connotation and associated it with blame and defensive reactions. Alternative, more acceptable terms were suggested which included ‘conflict’, ‘challenge’, ‘(difficult) situation’ or ‘problem’.

Emotional Quality

Most members of staff perceived dilemmas as personally challenging and evoking an emotional reaction in them. A number of participants felt that they needed to call on support and advice from colleagues or other professionals in an effort to cope.

Need for ‘objectivity’

Staff provided numerous descriptions of their attempts to remain mindful of and consider the multiple perspectives and divergent agendas held by other professionals and families. Participants talked about the need to account for and remain mindful of external factors that may impact on decision-making. There was a sense that participants needed to contain or distance themselves from the emotional response evoked in them by dilemmas in order to comply with what was expected of them as professionals.

Managing multiple perspectives

This theme highlights staff’s discomfort when faced with multiple opposing perspectives brought about by dilemmas and their struggle to make decisions knowing that they will impact on other people including the child, family and themselves in a number of ways. Participants’ accounts illustrated that staff were motivated by a wish to achieve best practice and prioritise families. Staff had

different views about whether certainty could ever be achieved and compromise was inevitable or not.

HAVING PERSPECTIVE ON LIFE

A unique position

Staff expressed an appreciation of their opportunities to build long-term relationships with families of children with LLCs whilst they remained aware that death was inevitable. Families' willingness to allow staff into their lives led participants to gain unique insights into families' lives. This unique position facilitated a reciprocal process of learning from families and using the knowledge and insight to support other families and it helped staff to cope with dilemmas.

Knowing what is important

Participants' accounts highlighted a heightened awareness of death and appreciation of the preciousness of life. This encouraged staff to reflect on their own lives and focus on what was important both in their personal and professional lives. Staff talked about appreciating their own families, having a greater perspective on their own worries and focusing on the important things at work, such as a 'being' with families as opposed to undertaking care-directed activities.

'Skewed perspective'

Staff's heightened awareness of death and their unique experiences at work also led them to experience conflict: staff talked about a tendency to diminish the value and importance of day-to-day struggles in their personal lives in comparison to the life-death experiences at work which they often perceived to be of a greater magnitude.

MOVING BETWEEN THE PERSONAL AND PROFESSIONAL

Professional identity

Participants' accounts demonstrated that staff frequently drew on their professional identity for guidance and reassurance and to help them cope with dilemmas. Decision with regards to which option to pursue were commonly led by

staff's professional codes, competence and duty of care for children even when these risked jeopardizing their relationships with families or other professionals.

Personal resources

Participants talked about being influenced by aspects of their personal identities. Identifying as a carer or mother or having a strong sense of one's upbringing and family values seemed to help staff make sense of their experiences. Although not consistently voiced, a few participants also drew on spiritual beliefs or their faith to help them make sense of dilemmas.

Self-care

All staff talked about the importance of self-care in order to cope with the demands of work. Their work seemed to create proximity requiring staff to engage in coping strategies to decrease stress levels. Staff talked about the benefits of coping strategies that helped them to create both a physical and emotional distance from work such as taking breaks, leisure activities or socializing and maintaining boundaries and an emotional distance with families.

Lack of division

Participant accounts illustrate a lack of division between their personal and professional identity; these seemed to be inter-connected and to overlap. Participants seemed to constantly move between the personal and professional realms and talked about the importance of acknowledging their human side. Whilst they made efforts to remain professional, they also talked about the need to reveal aspects of their personal selves when interacting with families.

SUPPORT : SHARING THE BURDEN

Support structures

Staff engaged with various sources of support to help them share the demands of their work and cope with dilemmas. These included informal peer supervision, (in)formal support from senior members of staff and group supervision. Support structures such as a telephone helpline which could meet both staff's personal and professional needs were also discussed. Some participants talked about additional psychology services for families as desired forms of indirect support to

clinical staff. The value of supervision was discussed extensively; accounts varied with regards to what constituted 'proper' supervision and a distinction was drawn between clinical and management supervision.

Feeling supported

Staff talked about the importance of having opportunities to offload and share with colleagues and the value of having senior staff on hand who were approachable and available to them when needed. Supportive management seemed to facilitate a supportive team culture and made staff feel valued, affirmed and backed up.

Desire to feel connected

The majority of participants expressed a desire to have more opportunities to get to know and connect with colleagues beyond the realm of work. Suggestions for these included regular away days, social gatherings and protected lunch breaks. They hoped that this would help them to increase cohesion and reduce pressure amongst the teams.

Appendix Q: Final Themes

Super-Ordinate Themes and Corresponding Sub-Ordinate Themes

SUPER-ORDINATE THEMES	SUB-ORDINATE THEMES
Dilemmas: Familiar Yet Uncomfortable	<ul style="list-style-type: none">• Negative Connotations• ‘Something’s Stirred Up in You’• Negotiating Multiple Perspectives
Greater Perspective on Life	<ul style="list-style-type: none">• Being in a Unique Position• Knowing What is Important• ‘Skewed Perspective’
Moving between the Professional and Personal	<ul style="list-style-type: none">• Professional Identity• Personal Identity, Values and Beliefs• Creating a Distance – Self-care• Blurring of Professional and Personal Identity
Sharing the Burden	<ul style="list-style-type: none">• Creating a Shared Understanding• The Value of Clinical Supervision• Space for Connecting with Each Other

Appendix R: Example of an Edited Quote

Original text:

I: And the word 'dilemma', does that fit with you? Would you [pause] use the word in everyday practice or do you think of dilemmas? Or is there another word that encapsulates that complexity

P: Dilemmas are just an – I guess, it's what I live with anyway as a therapist when you're talking to people and they're telling you aspects of their life

I: Mmh

P: and the narratives of their lives that [pause] hmm [pause], the things that they are telling you [pause] speak of dilemmas. (Anna, 606-615.)

Edited text:

I: And the word 'dilemma', does that fit with you? [...] Or is there another word that encapsulates that complexity?

P: Dilemmas are just an – I guess, it's what I live with anyway as a therapist when you're talking to people and they're telling you [...] the narratives of their lives that [...] [pause] speak of dilemmas. (Anna, 606-615.)

Appendix S: Reflective Journal Extract

Today I interviewed [Name of participant]⁷ and her account of her work was very interesting but it also left me feeling a bit unsure, sad and as though I had not been able to do enough for her today. In fact, it left me feeling confused about my role during the interview process and my ability to be a 'proper' researcher. Am I able to suspend my experience and status as a trainee psychologist or therapist when I am so used to being with and talking to people in a certain way? Whilst on the surface our conversations may not be so different from a 'therapy conversation' – I'm still trying to facilitate a therapeutic and helpful encounter with the person opposite me – the circumstances that led to our conversation are quite different. Of course, I am hoping that interviewees will benefit from our conversation by sharing their experiences and expertise, by feeling listened to and hopefully by gaining some helpful insights into the difficult aspects of their work and what might help them deal with these. Most importantly I hope that having their voice heard will make them feel valued and proud about the difficult work that they do on a daily basis. They might even learn from each other when receiving feedback about the findings from this study. However, there is no getting away from the fact that they have been asked by me to volunteer their time for my benefit of conducting this study. This creates a certain dynamic in the room, a power imbalance (that arguably is not so different in therapy) but I wonder whether I have been explicit enough with participants about my role during interviews? The lady was very insightful about how work was filling 'a void' in her life after having brought up two children who were becoming more and more independent and no longer needed their mother as much as they used to. Really, she talked about going through a transitional phase, trying to find herself and discovering new sides to her which she had not been able to

⁷ The participant's name and pseudonym were purposely omitted to preserve her anonymity.

attend to for so long. It felt as though work was one of these new discoveries and was incredibly important to her as it gave her a purpose in life and left her feeling valued and useful. There were a number of times during the interview where she revealed just how big a part work was taking up in her life and how tempting it was to give too much or loose herself in work given that there was not too much else in her life. I got a real sense of how much she enjoyed the human contact and relationships at work with the families and colleagues she worked with but also the emotional impact work could have on her and how much her passion for work highlighted what she was missing in her life. She talked about a lack of friends in her life and her difficulties in sharing her experiences with her husband. This made me wonder whether she had sought this opportunity for that very purpose that is to talk and offload, which was not always possible in her own life. Her story also reminded me of my own mother who had experienced a similar struggle when I and my siblings left home and she was confronted with an emptiness in her life after having been a full-time mother for so long. Like in a therapy session with a client, I was aware of the feelings she was evoking in me in the transference and my attempts to resist responding to this by offering reassurance or encouraging further exploration. At the same time, however, I felt confused about my role and slightly irritated by how honest she was and how much she was sharing. It crossed my mind that our encounter was also confusing for her and led her to think of our interview as something like therapy or supervision as opposed to a research task. I was trying to achieve a difficult balance. One the one hand, I wanted to stick with conducting a research interview and not get side-tracked by one of many other interesting stories she was sharing; but on the other hand, I also wanted to acknowledge how difficult her experiences were for her and share my appreciation for allowing me to gain insight into her life. I think I managed a bit of both by reflecting to her how hard her experiences felt whilst also reminding her of the time frame for our

interview and encouraging her to share more about this topic should she we have sufficient time at the end of the interview should she wish to do so. However, I also found myself going too far the other way at one point during the interview, which felt very uncomfortable when I recognized that through my response, i.e. to change the topic, I colluded with all the people in her life who did not seem to listen or understand her which she struggled with so very much. I remember asking her the next question when she told me how hard it was for her to feel understood by her family members, particularly her husband which often stopped her from talking about her experiences at work even though she had a real need to share and express her distress. I became aware of this before our encounter ended and managed to spend a few minutes talking to her once the recording had finished. I was able to thank her for being so honest and open and let her know that I had managed to get a real sense of how difficult things were for her at times. She responded very positively, thanking me for the opportunity to share her experiences and complimented on my style and ability to make connection between the various aspects of the stories she told me and how she had found this helpful and useful. This led me to appreciate that our encounter had been a two way interaction that had been useful and insightful for both of us even though we may have come to the interview with various ideas of how this might benefit or help us. It also made me reflect on how our personal and professional selves and stories are very closely connected and often hard to disentangle. I felt relieved that I was able to give her a copy of the debriefing sheet with contact numbers to call should she wish to talk to someone anonymously. Whilst I had often thought of debriefing sheets as a bit of a tokenistic gesture – I had certainly never used the information when taking part in research - this actually made me realize how important it was to be able to leave something with the interviewee. A bit like a transitional object which may help interviewees to remain connected with their experience and

provide comfort. More importantly, however, it felt comforting and reassuring for me to provide this lady with some information and contact numbers should she wish or need to talk more after our encounter. I hope that by doing so she felt a sense that her participation was valued and of importance.