The experiences of staff at children's hospices who use 'cold' facilities to care for families after the death of an infant: A qualitative study

Meghan Jeanne Waugh

Doctorate in Clinical Psychology Thesis, 2018

University of East Anglia

Faculty of Medicine and Health Sciences

University registration number: 100107661

Thesis portfolio word count: 29,420 (excluding appendices)

Thesis Portfolio Abstract

Background: Children's hospices in the UK have developed to incorporate various 'cold' facilities, which allow families to spend time with their baby after they have died. To date, no research has explored the impact on staff of providing this form of care alongside their usual roles within the hospice. This thesis aims to understand the experiences of stress in those providing palliative care through a systematic review, and explore the experiences of staff who are supporting families using 'cold' facilities within a paediatric hospice after the death of their infant.

Methods: A mixed-method systematic review and narrative synthesis of the literature was conducted using electronic databases and relevant reference sections of papers to evaluate the experience of stress in staff members who provide care in palliative services. Alongside this, a qualitative study was conducted using semi-structured interviews with seven members of staff at regional children's hospices to explore their experiences and the sense they made of their work. Data were transcribed and analysed using thematic analysis.

Results: The systematic review found 12 studies which met the inclusion criteria. Quality was appraised and data was analysed using narrative synthesis. Results reported the levels of stress, types of stressor and coping strategies identified. The thematic analysis of the qualitative study identified two key themes ('Challenges within the pathway' and 'Ways that challenges are met') and 12 subthemes.

 Conclusions: The research highlighted the unique experiences of staff in providing care using 'cold' facilities. Some challenges are specific to this care pathway, though others appear in line with those faced in overall paediatric palliative care. Challenges are ameliorated through both cognitive and behavioural coping mechanisms and the

importance of an open and supportive workplace culture is emphasised in ensuring staff

well-being. Limitations and directions for future research are considered.

Table of Contents

Acknowledgements

I would like to thank my primary research supervisor, Kiki Mastroyannopoulou, for her on-going support and encouragement throughout the research process. You have made it a rewarding pleasure to explore and reflect on such an emotive area of research, and I am grateful for your calm guidance and patience with me through the ups and downs of research. I would also like to thank senior staff at the hospices for their extensive help and support with the design of the study and recruitment; your flexibility and support were vital to completing the research. Most importantly, thank you to the people who gave up their time and spoke to me with such warmth, honesty and openness about their incredible work, without whom this thesis would not be possible.

Thank you to all of the wonderful people in my life who have supported me throughout my long clinical journey, particularly when times were bleak. To my mom and Nigel, thank you for everything you have done for me over the years; you have had a lot more belief in me than I have and your faith and love has meant the world to me. To my excellent brother, Duncan, for no real reason except for being a pretty okay human and a lifelong best friend. To my dad for wanting both Duncan and me to have all the experiences and adventures we could in life, even when that meant us living 4,000 miles away to have them. To my incredible friends both old and new; thank you for being so patient and sticking with me, I couldn't have done it without your support, advice, consolation and reality checks. None more so than my long distance beefs Hannah and Ally, for talking me through every major and minor life event in recent years; every decision I've made has been made by committee and you've both helped keep me sane. To Martin (KoD), for being my favourite person, and the loveliest thing to have come from a broken ankle. Macedonian praise, praise, praise.

Introduction to the thesis portfolio

Chapter 1 is a systematic review following a mixed-methods approach for assessing the qualitative, quantitative and mixed-method studies investigating stress specifically in staff providing care within palliative services. With an evidence base predominantly exploring nursing stress, this review adds to the evidence base by exploring the contemporary evidence base of stress in all care staff involved in palliative services.

Chapter 2 is a bridging chapter linking the experiences of stress in palliative care to the empirical study of the experiences of staff in a specialist care pathway within children's hospices. These staff members care for families after the loss of an infant, and also care for the infant's deceased body through 'cold' facilities. This chapter details 'cold' facilities generally and the neonatal pathway within these hospices. It also considers the context of working alongside death in Western society.

Chapter 3 is an empirical paper exploring the experiences of the staff who use 'cold' facilities to care for families after the loss of an infant. The study explores how staff members make sense of this work alongside their usual roles within the children's hospice, and the ways in which they manage any difficulties as part of this care pathway.

Chapter 4 is an in depth methodological section detailing the work presented in Chapter 3.

Chapter 5 is a critical analysis which includes a more detailed discussion of the results from Chapter 3, the strengths and limitations of this thesis portfolio, future directions for research and the clinical implications of the findings presented in Chapter 3.

Chapter 1.

Systematic review prepared for submission to: Palliative & Supportive Care

A mixed-method systematic review of the experience of stress in staff who work within palliative care

Meghan J. Waugh[a] and Kiki Mastroyannopoulou[b*]

[ab]*Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom*

*Correspondence concerning this article should be addressed to Kiki Mastroyannopoulou, Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom.

Email: k.mastroyannopoulou@uea.ac.uk

Total word count: 7676

Word count excluding abstract, table and references: 4998

Abstract

Objectives Providing end-of-life care is acknowledged as a challenging area of work. A large body of research exists on understanding stress in nurses, specifically those who work in palliative care. However, research is limited in looking at the wider staff groups who care for dying patients. This narrative synthesis reviews the literature on the experiences of stress in staff members who provide care in palliative services.

Methods A systematic review was conducted to identify relevant peer-reviewed research. Databases included PsychInfo, PsycArticles, Allied and Complementary Medicine Database, Cumulative Index to Nursing and Allied Health Literature, MEDLINE, Social Science Citation Index and the Cochrane Library, and 12 studies were included in the final review (seven quantitative, four qualitative and one mixed-method). Study quality was rated using the Mixed Method Appraisal Tool (MMAT) for mixed-method reviews, and data was extracted and synthesised narratively.

Results From the tabulated results, overall themes were identified within the data. These included levels of stress/burnout, types of stressors and coping strategies for managing stress. Reports on stress levels varied significantly, with some studies reporting high stress and others reporting low. This reflects differences in methodology, instruments and settings. Types of stressor included organisational and environmental stressors, relationships within the organisation and stressors related to patient or family care. Coping strategies emphasised a variety of self-care techniques and support received from both within the organisation and externally.

Significance of Results Stressors in multidisciplinary staff providing care within palliative settings appear similar to those reported in studies with nurses, though a number of limitations make generalising difficult. Further research should explore palliative care

settings independently and focus on including all staff providing a caring role to dying patients and their families.

Word count: 281

Introduction

Overall, in 2015/2016 stress accounted for 45% of all working days lost due to ill health in the UK (Health & Safety Executive [HSE], 2016). Work-related stress can be conceptualised as a person's perceptions of workplace demands and their ability to meet these demands (Lazarus & Folkman, 1984). The HSE (2016) found that professional occupations have the highest levels of work-related stress, and within this group, nursing and midwifery professionals were the largest contributors for high stress. For the purposes of this review, work-related stress is considered from the demand-control-support model proposed by Johnson and Hall (1998), which posits that strain at work comes from a combination of high demands, low autonomy in meeting these and a lack of support from both peers and managers. Healthcare workers in the NHS have also been found to have higher psychiatric morbidity than the general population (Wall et al., 1997) and are at risk of burnout. Burnout is defined as the chronic experience of emotional exhaustion, depersonalisation and lowered sense of personal accomplishment that can often occur in response to the repeated stressors of working with other people, particularly in public service (Maslach, Schaufeli & Leiter, 2001). Particularly relevant to nursing is the related and often conflated concept of compassion fatigue, which is the traumatising emotional state of caregivers who become engrossed in the suffering of those they care for (Figley, 2002; Showalter, 2010). It is defined as a physical and mental exhaustion caused by the convergence with burnout, resulting in a diminished ability to cope with the demands of work (Cocker & Joss, 2016).

Providing end-of-life support for patients is a specialist area of healthcare, with a number of stressors for staff related to the unique and emotionally charged nature of the work (Brenner, 1997; Keidel, 2002; Mackereth, White, Cawthorn & Lynch, 2005). In addition to commonly reported stressors of nursing which include long hours, complex and varied tasks, and complicated relationships with patients, families and other professionals

(Maslach et al., 2001, Shimizu, Mizoue Kubota, Mishima, & Nagata, 2003), those involved in palliative nursing encounter further stressors including watching patient suffering, talking to patients about their impending death and the eventual death of patients (Burnard et al., 2008; Wenzel, Shaha, Klimmek & Krumm, 2011). Despite this, research has shown that palliative nurses report experiencing less stress than other nursing disciplines (Gray-Toft & Anderson, 1981; Plante & Bouchard, 1996; Power & Sharp, 1998; Tyler & Ellison, 1994).

In contrast with other areas of healthcare where the emphasis is on either maintaining or improving an area of functioning (Georges, Grypdonck & Dierckx de Casterle, 2002), palliative care focuses on the needs of the dying and their families, and aims to relieve suffering rather than effect a cure (Macpherson, 2002). It is a holistic approach to care that aims to maintain or improve the quality of life for those with life-threatening conditions and their families, through physical symptom relief, pain management, and additional supportive care for any social, psychological or spiritual needs being faced in coping with illness and death (National Institute for Health & Care Excellence, 2004; World Health Organisation, 2009). To date, research on staff stress in palliative care has primarily focused on nurses. Their role has been found to encompass a number of dimensions, both practical and attitudinal, and includes valuing, connecting, empowering, doing for, finding meaning and preserving own integrity (Davies & Oberle, 1990). The relationship between professional caregiver and patient is thus perceived to be central to providing good palliative care (Athlin, Furåker, Jansson & Norberg, 1993; Cooper & Barnett, 2005; Nordgren & Olsson, 2004; Rittman, Paige, Rivera, Sutphin & Godown, 1997; Taylor, Glass, McFarlane & Stirling, 1997). Davies and Oberle (1990) suggest that the palliative nurse as a professional cannot be separated from the nurse as a person. This sustained compassionate care places nurses working in end-of-life care at risk of emotional exhaustion and compassion fatigue (Aycock & Boyle, 2009).

In addition to stressors related to the nature of palliative care, there are increasing demands on staff from workload and organisational perspectives which add to the experiences of stress in this staff group (Hawkins, Howard & Oyebode, 2007). In an ageing population with medical advancements prolonging the lives of both the elderly and those with complex and life-limiting conditions, there has been a consistent increase in those using hospice and palliative care services (Help The Hospices Commission, 2013) with predictions of death rates in England increasing substantially in the coming years (Higginson, Calanzani & Gomes, 2013).

Since the modern hospice movement began in the 1960s (Stoddard, 1978), a number of studies have centred on occupational stress in palliative care (for a review, see Vachon, 1995) with a focus on nurses in particular (for a review on nursing stress in palliative care, see Peters et al., 2012). However, hospice care has evolved into a multidisciplinary approach (Connor, 2009) which ordinarily includes additional supportive care from healthcare or nursing assistants, counsellors, social workers and chaplains (McConnell, Porter & Scott, 2016). The role of providing holistic and humane support in palliative work clearly now extends beyond nurses. Increasingly, palliative care is provided in a number of different settings including acute inpatient wards, specialist palliative inpatient units, care homes, hospices or in-home (Peters et al., 2012). To this end, this review considers studies of stress and coping more widely in care staff across the various settings used in providing hands-on palliative care.

Research Question: What are the contemporary experiences of stress (or burnout, or compassion fatigue) in staff members providing care in palliative services?

Methods

Inclusion/Exclusion Criteria

The literature was reviewed systematically using the following criteria:

Inclusion:

- Peer-reviewed journals

- Empirical papers (qualitative, quantitative or mixed-methods)

- Construct: Investigating stress or coping

- Population: Study utilises a mixture of employed front-line care staff (e.g. nurses, healthcare assistants, nursing assistants, support workers, counsellors)

- Setting: palliative care (inpatient or at-home/community) or hospice

Exclusion:

- Studies published prior to 1995

- Review papers

- Commentary papers

- Studies did not report findings for palliative care staff specifically

- Population did not include front-line care staff other than nurses

- Population was primarily physicians

- Investigating stress of end-of-life care in general nursing/medicine

Search Strategy

Studies were identified through searching seven databases: PsychInfo, PsycArticles, Allied and Complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, Social Science Citation Index (SSCI) and the Cochrane Library. Searches were run in March 2017 and October 2017 prior to writing.

The search terms used were: ("end of life" OR "hospice" OR "palliative" OR "dying" OR "death" OR "dead" OR "terminal") AND ("stress" OR "burnout" OR "burn-out" OR "burn out" OR "fatigue" OR "coping" OR "'cope" OR "wellbeing" OR "well being" OR "well-being") AND ("staff" OR "nurs*")". Reference lists of relevant papers were reviewed to identify additional papers, and key journals were also searched separately to ensure all relevant papers had been identified. These journals included *Palliative Nursing, Palliative & Supportive Care, American Journal of Palliative and Hospice Care, International Journal of Palliative Nursing, BMC Palliative Care, Palliative Medicine,* and *Journal of Advanced Nursing.*

Electronic searches yielded a total of 1565 results and a further 5 papers were identified through hand searches. The full search process is detailed in Figure 1, which follows the PRISMA guidance (Moher, Liberati, Tetzlaff, Altman & The PRISMA Group, 2009). Duplicates were removed from the results, and the remaining 902 studies were initially screened for inclusion by title and journal type. Of these, 740 were removed which were clearly not relevant, the majority of which were in areas unrelated to palliative healthcare (e.g. veterinary sciences, neuroscience, developmental neurobiology) or which clearly investigated solely patient or caregiver experiences as opposed to experiences of staff. Of the remaining 143 studies reviewed by title and abstract, 54 articles appeared to meet criteria and were reviewed in full against the inclusion and exclusion criteria."

Assessment of Quality

As methodologies varied across the included studies, quality of each study was assessed using the MMAT (Pluye et al., 2011). The MMAT is a well utilised and validated tool (Pace et al., 2012) for mixed-method systematic reviews which allows for an assessment of the rigour of qualitative, quantitative and mixed-methods designs alongside each other.
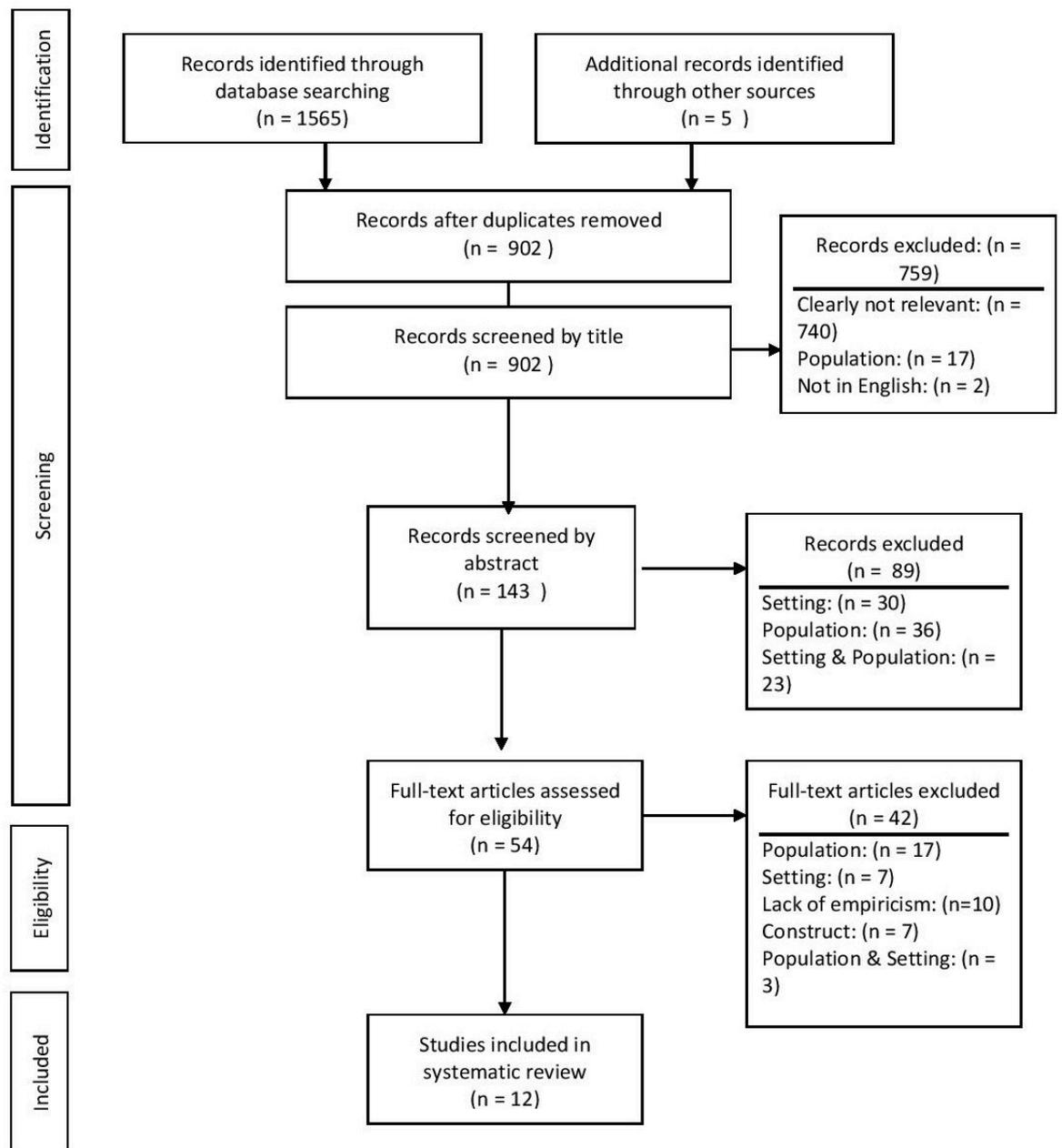
Figure 1: PRISMA flow diagram

As none of the studies involved interventions, widely used quantitative assessment

methods were not deemed appropriate for use on the included data. With the MMAT,

papers are given a percentage score of the number of criteria met out of 6, with differing

criteria based on whether the methodology is qualitative, quantitative or mixed methods.

Full criteria used from the MMAT can be found in Appendix A. All 12 papers were

included in this review for completeness, but quality was considered in reviewing the trustworthiness of the data. It was also decided to include all papers as structured methods to assess the quality of qualitative papers specifically have been shown to have large amounts of disagreement (Dixon-Woods et al., 2007). All papers were appraised by a second independent researcher, L.S., and minor discrepancies were discussed until an agreement was reached on appraisal scores. For 10 out of 12 papers, there was 100% agreement. On two papers, there was an initial discrepancy of one point on each of the appraisals. In both cases, the researcher giving the higher score explained the marking and it was mutually decided whether the higher or lower score was deemed more appropriate.

Data Analysis

With varied methodologies and studies not focused on a treatment intervention, a narrative synthesis approach was adopted to analyse the data (Popay et al., 2006; Thomas, Ciliska, Dobbins & Micucci, 2004). This was conducted in line with guidance from the Cochrane group on narrative synthesis reviews (Ryan, 2013). A narrative synthesis allows the researcher to maintain a systematic structure to the review whilst acknowledging that it is a general framework rather than a prescriptive tool (Popay et al., 2006).

The first stage of analysis involves tabulating the data in a visual format to provide basic descriptions of the reviewed studies (Popay et al., 2006). Headings were chosen to approximate recent literature reviews of stress in hospice nursing (Peters et al., 2012) and experiences of end-of-life care with children (McConnell et al., 2016), both of which followed a similar methodological approach to synthesis. Qualitative descriptions were then constructed to synthesise the reported outcomes of each of the 12 studies, with an additional assessment of the study quality in line with MMAT guidance (Pluye et al., 2011. The final stage of analysis involved exploring similarities and differences amongst the studies (Higgins & Green, 2011) and a discussion of the robustness of the synthesis (Popay et al., 2006).

Results

Reviewing the literature identified a total of 12 studies investigating stress in palliative care staff, of which seven were quantitative studies employing cross-sectional designs (Hackett, Palmer & Farrants, 2009; Koh et al., 2015; Montross-Thomas, Scheiber, Meier, & Irwin, 2016; Payne, 2001; Pierce et al., 2007; Slocum-Gori, Hemsworth, Chan, Carson & Kazanjian,, 2011, Whitebird, Asche, Thompson, Rossom & Heinrich, 2013), four were qualitative studies (DiTullio & MacDonald, 1999; Hackett & Palmer, 2010; McConnell & Porter, 2017; Tunnah, Jones & Johnstone, 2012) and one was a mixed-method study (Loes van Staa, Visser & van der Zouwe,, 2000). All studies included nurses in their samples, with two studies primarily looking at nurses and either nursing assistants or healthcare assistants (Tunnah et al., 2012; Payne, 2001). Six studies included all members of staff (DiTullio & MacDonald, 1999; Hackett et al., 2009; Loes van Staa et al., 2000; Montross-Thomas et al., 2016; Slocum-Gori et al., 2011; Whitebird et al., 2013), and four included all clinical staff members (Hackett & Palmer, 2010; Koh et al., 2015; McConnell & Porter, 2017; Pierce et al., 2007). Of the included studies, seven were set in hospices, one involved at-home hospice care, two were set in inpatient palliative units and two were set in a variety of palliative services. The country, design, instruments, settings and outcomes are presented for each study in *Table 1*.

There was overlap in the construct of stress, which is reflective of the general difficulty in defining and operationalising stress. Therefore, included are studies which investigated burnout, as well as compassion fatigue, as these concepts both incorporate stress. Quantitative studies used a combination of validated and idiosyncratic measures. Validated measures on stress and burnout included the Nursing Stress Scale (NSS), the Depression Anxiety and Stress Scale 21 ([DASS 21] Lovibond & Lovibond, 1995), and the Maslach Burnout Inventory ([MBI] Maslach & Jackson, 1981). The MBI consists of three subscales which measure emotional exhaustion (EE), depersonalisation (DP) and personal

accomplishment (PA). Compassion fatigue was investigated using the Professional Quality of Life scale ([ProQOL-III] Stamm, 2002) which includes subscales on compassion satisfaction, burnout and compassion fatigue. Coping was measured using the Way of Coping Checklist ([WCCL], Folkman & Lazarus, 1988). Of the qualitative studies, one used focus groups, one used semi-structured interviews and two used a combination of semi-structured interviews and focus groups.

The results of the review are explored under the themes identified from the tabulated results, which include: levels of stress/burnout, types of stressors and coping strategies for managing stress.

Levels of Stress/Burnout

The interpretation of what makes a situation stressful varies from person to person, and the same event may not be perceived as stressful by each person experiencing it (Lees & Ellis, 1990; McVicar, 2003; Vachon, 1995). Eight quantitative studies reported on levels of stress or burnout experienced in palliative care staff, using a range of validated and idiosyncratic measures. Results of stress and burnout levels vary.

In a study by Hackett et al. (2010), stress, anxiety and depression levels in all types of staff members at two UK hospices (n=91) were compared to the overall population using the DASS-21 and HSE Stress Indicator Tool. They found that staff did not report higher levels of strain on the DASS-21 than the general population, and also scored 3% lower on stress than the NHS reported average.

Koh et al. (2015) investigated burnout rates and psychological morbidity in a large sample of staff working across a range of public sector palliative care services in Singapore (n=273). Participants included nurses (58.3%), physicians (28.1%) and social workers (13.6%), and the study used the MBI, Human Services Survey and General Health Questionnaire. The study found a 33.3% burnout rate within respondents, with 28.2% of

participants being at risk of psychological morbidity. The study found that staff providing at-home hospice services were more at risk for psychological morbidity than staff in hospice or inpatient palliative settings. They additionally found that those working more than 60 hours per week and working across multiple sites were more at risk of burnout. Payne (2001) investigated stress and burnout in nurses and nursing assistants using the MBI, NSS and WCCL (n=82). Results indicated that staff identified emotional exhaustion was linked with 'death and dying', 'accepting responsibility' and 'conflict with staff' as well as higher nursing grade. They also found that 'stressors' contributed most to the experience of burnout, while demographic characteristics contributed least. Overall stress was reported to be low compared to other areas of nursing care, though results from the NSS were not reported.

Loes van Staa et al. (2000) assessed stress levels after opening an academic palliative care unit in the Netherlands by way of an idiosyncratic questionnaire. They found staff (n=24) were significantly more stressed after one year of working in the new service. Using an idiosyncratic questionnaire, Pierce et al. (2007) identified staff on both a palliative care unit (PCU) (n=25) and an oncology inpatient unit (OIU) (n=35) reported experiencing 'a great deal of stress'. Staff on the PCU reported this less (52%) than staff on the OIU, however (71%). It is worth noting that the MMAT score is particularly low for this study, and trustworthiness should be treated with caution.

Table 1

Summary of studies included in the systematic review

Author, Year & Location	Setting	Participants & Sample Size	Design & Methods	Aims	Instruments/Measures	Outcomes	MMAT Appraisal
DiTullio & MacDonald (1999), USA	Hospice	N=38 (All types hospice staff)	Qualitative (grounded theory)	Create understanding of stress in hospice; create a model of stress in hospice care.	Semi-structured interviews and three group meetings analysed with grounded theory.	Authors identified the following themes to stressors, listed in rank order frequency: "time cramping" (71%), "emotional cramping" (55.3%), "Volume/diversity/complexity of demands" (55.3%), "insufficient response up the line" (55.3%), "faulty communication, system malfunction" (55.3%), "policy cramping" (52.6%), "unpredictability/distraction/discontinuity" (47.4%), "inadequate pay/job insecurity" (34.2%), "lack of appreciation/support at work" (31.6%), "paperwork" (28.9%), "interpersonal stress/tension/"politics"" (28.9%), "impingement of personal loss/stressors" (28.9%), "lack of input in agency policy" (23.7%) and ""controlling" co-workers" (18.4%). Themes to coping strategies were: "relaxation/meditation/self-soothing behaviour" (61.7%), "relationships outside hospice" (44.1%), "maintaining inner balance/"centering"/acceptance" (44.1%), "relationships inside hospice"(41.2%), "humor" (32.4%), "personal organization/time management" (32.4%), "physical exercise" (29.4%), "hobbies/interests" (29.4%), "personal spirituality and faith" (26.5%), ""the work itself" (26.5%), ""setting boundaries/confronting/saying "no"" (20.6%), and "mental reframing" (20.6%).	Researcher reflexivity only partially addressed QUAL 5/6

Hackett, Palmer & Farrants (2009), UK	Hospice	N=91 (All types of hospice staff)	Quantitative (cross sectional design)	Understand stress and coaching needs in hospices. How do stress, depression and anxiety levels compare to the overall population, what are the needs of this group.	Depression, Anxiety & Stress Scale (DASS-21), Health & Safety Executive (HSE) Stress Indicator Tool, demographic questionnaire.	Whether people understand their role in the organisation was shown to predict stress. Found that staff displayed less stress, anxiety and depression than overall population, but identified stressors of: role demand, manager's support, workplace relationships and change.	Minimal a priori sample not met, did not recruit from multiple hospices. QUAN DES 4/6
Hackett & Palmer (2010), UK	Hospice	N=12 (Mixture of nurses and other clinical staff)	Qualitative (grounded theory)	To investigate in depth the stressors and demands in hospice care, and establish whether coaching would be beneficial.	Two focus groups analysed with grounded theory.	Identified specific demands within the subheadings of clinical, training, emotional, time and the new NHS. Discussions emphasised the need for thorough staff supervision and support, to cope with the various demands.	Researcher reflexivity not addressed. QUAL 5/6
Koh et al. (2015), Singapore	Public sector palliative services	N=273 (Mixture of nurses: 58.3%, physicians : 28.1%, and social workers: 13.6%).	Quantitative (cross-sectional design)	To investigate burnout rates and psychological morbidity in palliative care staff with high stress levels.	Maslach Burnout Inventory (MBI), Human Services Survey (HSS) & General Health Questionnaire (GHQ).	Identified a 33% burnout rate amongst respondents, and 28.2% of participants were at risk for psychological morbidity. Significant factors included working hours, gender, spirituality, Home-hospice workers were more at risk of psychological morbidity than those in hospice or inpatient settings. Those with more coping mechanisms showed lower levels of burnout. These included physical well-being, clinical variety, setting boundaries, transcendental (meditation and quiet reflection), passion for one's work, realistic expectations, remembering patients and organisational activities. Those who worked more than 60 hours per week and those who worked across multiple sites were also more at risk of burnout.	Did not report on response rate QUAN DES 5/6

Loes van Staa, Visser, & van der Zouwe, (2000), Netherlands	Hospital (palliative care unit)	N=24 (All types of staff)	Mixed method (pre and post change questionnaires)	To assess the impact of opening a new palliative care unit on the staff members, and assess stress levels over the course of 1 year.	Idiosyncratic questionnaires administered at four time points. Questions included views on palliative care and evaluation of the organisation, as well as "validated measures on stress, coping and work satisfaction" (not detailed). Staff were interviewed at each time point with "open ended questions" and results were analysed electronically through KWALITAN.	The authors reported that after 6 and 12 months of working at the PCU, staff were asked to assess the amount of job-related stress they experienced. Interviews revealed three primary sources of stress which included stress related to the organisation as a whole, stress related to team work and collaboration and stress related to direct patient care. In the second half of the first year, stress levels were found have risen significantly. The authors found that stressors were unrelated to palliative aspects of care.	Lacked methodological transparency, no validated measures used, and lack of detail in qualitative report. MIXED 2/6
McConnell & Porter (2017), Northern Ireland	Children's hospice	N=15 (11 nurses, three care assistants and one care manager)	Qualitative (thematic analysis)	To explore the impact on staff of providing end-of-life care to children, and investigate coping.	12 semi-structured interviews and one focus group (three participants) analysed with thematic analysis.	Themes emerged relating to the challenges of end of life care with children, including symptom management, communication with families, managing their own grief, and balancing complex respite care alongside end-of-life care. Staff identified strategies that helped mitigate against these difficulties, including self-care, peer support, organisational support, on-going training in communication skills, and dissemination amongst other hospice services to build expertise.	Researcher reflexivity not addressed QUAL 5/6
Montross-Thomas, Scheiber, Meier, & Irwin (2016), USA	Hospices	N=390 (All types of hospice staff and volunteers)	Quantitative (cross-sectional design)	Explore the role of personally meaningful rituals in hospice staff's experiences of burnout and compassion.	ProQOL subscales (Burnout, Compassion Satisfaction, Secondary Traumatic Stress), idiosyncratic questionnaire on rituals.	The majority of respondents used some form of personally meaningful ritual after the death of a patient (71%). These respondents showed lower levels of burnout and higher levels of compassion satisfaction. Increased compassion satisfaction was related to greater support, older age and more years of	Unclear research questions, sampling strategy only online. QUANT DES

							4/6
						experience, as well as religiousity/spirituality. A negative relationship was found with secondary traumatic stress, potentially related to the age and experience of the sample.	
Payne (2001), UK	Hospices	N=89 (72 palliative care nurses and 17 nursing assistants from nine hospice organisations)	Quantitative (cross-sectional design)	To investigate the level of burnout amongst hospice nurses and nursing assistants and identify which aspects of the role were related to any symptoms of burnout.	MBI, NSS, Ways of Coping Scale (WAYS) and demographic data.	Levels of burnout were found to be low in this population. Levels of Emotional Exhaustion and Depersonalisation were also found to be similar to previous hospice samples. In this study, multiple regressions showed that emotional exhaustion on the MBI was impacted on by the following factors: 'death and dying', 'conflict with staff', 'accepting responsibility' and higher nursing grade. Depersonalisation was related to 'conflict with staff', 'inadequate preparation', 'escape' and reduced 'planful problem solving'. Lower levels of personal accomplishment were related to 'inadequate preparation', 'escape', reduced 'positive reappraisal' and fewer professional qualifications. Stressors made the greatest contribution to burnout, while demographic factors contributed the least.	Low response rate QUANT DES 5/6
Pierce et al. (2007), Canada	Hospital - inpatient palliative care unit (PCU) and oncology inpatient unit (OIU)	N=70 (25 staff members on PCU - 64% nursing, and 35 staff members on the OIU - 76% nursing)	Quantitative (cross-sectional design)	A comparison of work-related stress and staff satisfaction on PCU compared to OIU.	Idiosyncratic 53-item questionnaire, including demographic information, self-care, coping, stress, professional satisfaction, perceived team support and personal attitudes to death.	Both wards reported experiencing a "great deal of stress", though this was less on the PCU (52%) than the OIU (71%). Both staff groups reported being able to control this work-related stress, and benefited from support from friends, family and other staff members, though PCU staff reported also benefiting from support from other professional groups. OIU staff found it more difficult to care for dying patients generally. Both sets of staff reported high work satisfaction. PCU staff reported positively altered views of death from carrying out their work.	Unclear about research question. Short length of follow-up. No validated measures. QUANT DES 4/6

Slocum-Gori et al. (2011), Canada	All palliative care services	N= 630 (All types of staff in hospice and palliative care organisations across Canada)	Quantitative (cross-sectional design)	To understand the relationship between compassion satisfaction, compassion fatigue and burnout across the palliative care workforce.	ProQOL subscales (Compassion Satisfaction, Compassion Fatigue and Burnout).	Types of service delivered in palliative care showed significant relationships with compassion fatigue and burnout. Higher levels of compassion fatigue and burnout were seen in those providing psychological care for patients and family showed a higher rate for compassion fatigue and burnout, emotional support for team members, and provision of relief from physical, psychological or spiritual pain in patients. Nurses also showed higher compassion fatigue than other professional affiliations. Part-time staff also showed higher levels of compassion satisfaction, with lower levels of compassion fatigue and burnout than full-time staff.	Unclear research question (exploratory), sampling strategy online only, unclear on response rate. QUANT DES 3/6
Tunnah, Jones & Johnstone (2012), UK	Hospice	N= 11 (10 community hospice nurses and one healthcare assistant)	Qualitative (grounded theory)	To understand the feelings and experiences of nurses providing hospice care at home.	Semi-structured interviews analysed with grounded theory.	Themes of job satisfaction, stressors, coping strategies and support were identified. Job satisfaction was identified as key to identifying stress levels. The participants also identified conflicts with other professionals as a source of stress, as well as the role being 'mentally draining'. Nurses identified a need to 'switch off' after work and find coping strategies. Support from colleagues was identified as an important part of coping.	QUAL 6/6
Whitebird et al. (2013), USA	Hospices	N= 547 (All types of hospice staff. Nurses: 37.3%, social workers: 11.5%, home	Quantitative (cross-sectional design)	To understand how stress affects the mental health of hospice workers. Particular focus on compassion fatigue and burnout.	Short Form 12 Heath Survey Version 2 (SF-12), Generalized Anxiety Disorder Scale (GAD-7), Patient Health Questionnaire (PHQ-8), ProQOL, Medical	60% staff reported moderate to high levels of stress, with a small proportion indicating moderate to severe symptoms of depression, anxiety, compassion fatigue and burnout. Stress was managed through social support, and physical activity, and staff identified that more opportunities to connect with co-	Unclear on research question, somewhat unclear on how sample was recruited.

health aides: 18.5%, administrative staff: 15.7%, bereavement/c haplaincy: 9.2% and volunteer/othe r: 6.5%)		Outcomes Social Support Survey – short form(MOS6).	workers and engage in physical activity would help to decrease burnout. Though stress is significant, it was found that it was not related to significant levels of poor mental health.	QUANT DES 5/6

Montross-Thomas et al. (2016) investigated the role of personally meaningful rituals in the experience of burnout and compassion satisfaction using the ProQOL in hospice staff and volunteers (n=390) across 38 states in the USA. Overall, they found staff scored in the 'low' range on burnout and secondary trauma, and were between 'average' and 'high' for compassion satisfaction. They found that the majority of participants (71%) used meaningful rituals in some way after the death of a patient, and these participants showed lower levels of burnout and higher levels of compassion satisfaction.

Whitebird et al. (2013) surveyed hospice staff in the USA (n=547) using the ProQOL and measures on depression and anxiety, and found that 60% of staff reported moderate to high levels of stress, with a small proportion indicating moderate to severe symptoms of depression, anxiety, compassion fatigue and burnout. Though stress was found to be high, this was not related to significant levels of poor mental health. In a study looking at staff across palliative services in Canada (n=630), Slocum-Gori et al. (2011) found that when compared to the literature on burnout and compassion fatigue, healthcare professionals across palliative services showed only slightly elevated levels of compassion fatigue and average levels of burnout. Significantly, staff who identified that their role was primarily involved in the 'assistance with provision of relief from physical, emotional and/or spiritual pain or distress' (p. 175) and 'providing emotional support to other team members' showed higher levels of compassion fatigue and burnout on the ProQOL. Additionally, nurses were the professional affiliation with the highest amount of compassion fatigue.

The studies are difficult to directly compare due to differences in research design and measures used. In line with the review of Peters et al. (2012), the inconsistent reporting of subscales also made it difficult to compare scores overall. Overall the picture appears mixed for levels of stress in front-line care staff in palliative settings, with half of the

studies reporting higher levels of stress or burnout and half reporting lower levels. As noted, previous studies of stress in palliative nursing have generally found lower levels of stress than nurses in other specialties, as have studies of stress in palliative care physicians when compared to other specialties (Graham et al., 1996; Ramirez et al., 1996). It may be that the experience of stress and burnout is different amongst different professional affiliations within palliative care. It may also be that the disparity in reported stress identified in this review reflects different stressors specific to different settings of delivering palliative care (Desbiens & Fillion, 2007). Martens (2009) identified that nurses providing at-home palliative care and those providing inpatient care differed in perceptions of stress, as well as perceptions of the most dominant stressors. Indeed, two of the studies in this review which found higher levels of stress and burnout (Koh et al., 2015; Slocum-Gori et al., 2016) were set across palliative services and found differences in stress and burnout levels based on where palliative care was provided.

Types of Stressors

Organisational/Environmental. The environment where staff work has been acknowledged as a key stressor in palliative care, with difficulties related to team communication, insufficient resources and role ambiguity (Vachon, 1995; Vachon, 1998; Hawkins et al., 2007). Organisational demands such as role demand, manager's support, and change were found to predict stress in a UK hospice (Hackett et al., 2009), and themes related to organisational stressors were frequently identified by DiTullio and McDonald (1999) in a hospice in the USA. They identified 14 frequently occurring themes, with 12 related to organisational or environmental issues. Similarly, Hackett and Palmer (2010) identified that stressors related to training, time and demands within the NHS were an issue for staff in a UK hospice. In establishing a new palliative care unit in the Netherlands, Loes van Staa et al. (2000) found that stressors were primarily related to the organisation, team work and collaboration. Tunnah et al. (2012) noted that conflicts with other external

professionals was a source of stress for nurses and healthcare assistants in a UK hospice. McConnell and Porter (2017) found that staff were challenged by the role demand of balancing complex respite care alongside providing end-of-life care in a children's hospice in Northern Ireland.

Results suggest that issues related to insufficient time, workload demands and other organisational difficulties were sources of stress for caring staff in palliative services. Most studies identifying organisational stressors were set in hospices, which supports other findings with nurses in hospice care (Ablett & Jones, 2007; Fillion et al., 2007); as well as nursing in palliative care more generally (Vachon, 1995).

Interpersonal Relationships. Interpersonal relationships at work have been found to be a possible buffer against the experience of stress at work (Viswesvaran, Sanchez & Fisher, 1999). Results from this review indicate that relationships in the workplace appeared to be a significant stressor across different settings in care staff in palliative services. Hackett et al. (2009) identified that workplace relationships predicted stress in hospice, and DiTullio and McDonald (1999) found that within organisational stressors, frequently occurring themes were a 'lack of appreciation/support at work' (31.6%), 'interpersonal stress/tension/'politics'' (28.9%), 'controlling co-workers' (18.4%). This is in line with findings suggesting that a lack of managerial support contributes to the experience of stress in nurses (Allen, 2001). DiTullio and MacDonald also noted that good workplace relationships helped staff cope with stress. Payne (2001) found that the emotional exhaustion and depersonalisation subscales on the MBI were partly impacted upon by 'conflict with staff'. Slocum-Gori et al. (2011) found higher levels of compassion fatigue and burnout on the ProQOL amongst staff who were providing emotional support to other staff members.

Patient/Family Focused. Stressors were also related to patient care, with this encompassing the emotional responses staff found stressful in caring for patients. Hackett and Palmer (2010) reported that staff found the emotional demands of caring work in hospice challenging, including the lengthy dying process, patient complaints and working with younger patients or patients with young children. McConnell and Porter (2017) identified that within a children's hospice, challenges included symptom management and communication with families. Payne (2001) found that emotional exhaustion on the MBI was impacted on by 'death and dying' and also 'accepting responsibility', which was conceptualised as 'self-blame'. DiTullio and MacDonald (1999) identified 'emotional cramping' as a significant stressor, which they defined as a lack of time for one's self-care, which staff related to a lack of time to process the losses from patient deaths. They also identified that the increasing complexities of patient presentations were a source of stress for staff.

In contrast, in a hospital setting Pierce et al. (2007) found that staff on the OIU struggled more than staff on the PCU in caring for dying patients. Similarly, Loes van Staa et al. (2000) found that although patient care was a source of stress, this stress was unrelated to palliative aspects of care in PCU staff.

Coping Mechanisms

A number of studies reported the ways in which staff managed their stress. DiTullio and MacDonald (1999) identified themes to coping strategies that staff used which included: 'relaxation/meditation/self-soothing behaviour', 'relationships outside hospice', 'maintaining inner balance/"centering"/acceptance', 'humour', 'physical exercise', 'hobbies/interests', 'personal spirituality and faith', 'setting boundaries/confronting/saying "no"' and 'mental reframing'. Koh et al. (2015) found that staff with more coping mechanisms showed lower levels of burnout on the MBI, which included: physical well-

being, clinical variety, setting boundaries, having realistic expectations and transcendental practices such as meditation and quiet reflection. Similarly, McConnell and Porter (2017) identified the importance of self-care in coping with the challenges of paediatric hospice care, which staff did by focusing on the positives of work, comfort from religion, mindfulness, keeping busy with housework, physical exercise, hobbies and talking to work colleagues. Coping strategies identified by Tunnah et al. (2012) and Whitebird et al. (2013) also included exercise and hobbies, and Tunnah et al. also emphasised the need to disengage emotionally after work.

In exploring personally meaningful rituals, Montross-Thomas et al. (2016) identified that staff who engaged in personally significant rituals after the death of a patient showed lower levels of burnout and higher levels of compassion satisfaction on ProQOL scales. They also identified that religiousness and spirituality, years of experience and increased age were associated with higher levels of compassion satisfaction.

Support was emphasised by Hackett and Palmer (2010), who found staff reported good peer support and local management support in particular, which the authors believed was facilitating the staff's ability to talk about negative experiences and thus moderate the impact of stress. The theme of both personal and professional support was also found by Tunnah et al. (2012) and Whitebird et al. (2013), and were highlighted by DiTullio and MacDonald (1999), who identified that various types and levels of support were seen not only as a reward to staff members but a significant resource for coping with stress. Similarly, both peer and organisational support were emphasised by McConnell and Porter (2017) as important for staff in coping with the challenges of paediatric palliative care, and Montross-Thomas et al. (2016) noted that high levels of personal and professional support were associated with high levels of compassion satisfaction.

Discussion

Findings from this review contribute to the understanding of stress experienced by the varied staff members involved in palliative care. The existing literature largely focuses on nurses, and this study adds to the evidence base by considering the stressors for other staff members providing palliative care alongside the existing literature on stressors in nurses.

Results indicate that understanding stress levels in palliative care staff is a complex picture, which is difficult to generalise. Understanding stress levels may depend on the measures used, the setting in which care takes place, the professional affiliation of staff, and the wider impacts of the country the research is conducted in. It may be that different challenges are reflective of working within different settings, which has been noted in studies looking at stress in nurses in settings such as at-home hospice care (Wilkes et al., 1998; Wilkes & Beale, 2001), hospital settings (Bruneau & Ellison, 2004; McConnell, O'Halloran, Donnelly & Porter, 2015) and hospices (Woolley et al., 1989, Dean, 1998; Harris, 2013). This may account for some of the variability in findings, particularly on levels of stress, which is supported by findings from two of the included studies (Koh et al. 2015, Slocum-Gori et al., 2011). Additionally, differences between working within privatised and public healthcare systems may impact on factors such as workload pressures, job security and organisational changes. Therefore future reviews could focus on either specific countries or specific palliative care settings in generating a clearer picture of stress in palliative care staff.

The types of stressors identified in palliative care staff are largely in line with findings for nurses (Abendroth & Flannery, 2006; Newton & Waters, 2001; Wallerstedt & Andershed, 2007) and are similar to those identified with providing end-of-life care with children (Barnes et al., 2001; McCloskey & Taggart, 2010; McConnell et al., 2016).

Results indicate that stress from organisational issues and stress related to difficult relationships within the workplace which lack support contribute to overall stress in wider caring staff in palliative services. This supports findings related to best-practice guidance on how to manage stress within hospices in particular (Lobb et al., 2010; McConnell & Porter, 2017; Tunnah et al., 2012; Woolley et al., 1989).

Despite difficulties in generalising across studies, there was a great deal of overlap in coping strategies reported to manage stress. Coping is a concept involving both behavioural and cognitive strategies to deal with the negative effects of stress (Chang et al., 2007; Lazarus & Folkman, 1984), and results indicate that there is a need for both to be utilised to manage stress in staff involved in caring for patients in palliative settings. In line with the wider literature, findings suggest that support from other staff members helps staff when providing end-of-life care (Dougherty et al., 2009; Lobb et al., 2010; Melvin, 2012; Wallerstedt & Andershed, 2007) and attempts to help staff deal with stress should focus on fostering a supportive culture within the workplace.

For the purposes of this review, all studies were included due to the paucity of research on stress which included care staff other than nurses. Additionally, the decision not to exclude studies of lower quality was made on the basis of the synthesis of qualitative studies being a subjective exercise. As noted by Bearman and Dawson (2013), qualitative studies are rich in detail but context specific, and therefore a qualitative analysis poses a risk of bias particularly without triangulation of multiple researchers conducting the review. However, the concept of replicability with a review of qualitative research is an epistemological challenge (Dixon-Woods et al., 2006) and therefore the decision to include all 12 studies also enables readers the opportunity to make conclusions about the studies which met the inclusion criteria.

Although all relevant studies were included, it should be noted that quality of the 12 included studies varied and therefore trustworthiness should be regarded with caution. Most studies scored between 4 and 6 out of 6, though Loes van Staa et al. (2000) were assessed as 2/6 and Slocum-Gori et al. (2011) were assessed as 3/6. A further limitation of this review is that it was conducted by one researcher. Though it was not possible for multiple reviewers to assess each study for inclusion as would be recommended (Thomas et al., 2004), results of the appraisal were triangulated through an independent researcher blind rating each included study. Despite this, this review is therefore a synthesis of one researcher's perspective who is interested in the study of stress in palliative care staff.

Though this review aims to assess the contemporary experiences of stress in varied caring roles within palliative services, research to date has predominantly focused on nurses. With palliative care expanding to involve multidisciplinary care in different settings, future research should look to understand staff experiences of stress as inclusively as possible. As one study found higher levels of compassion fatigue and burnout in those providing physical, psychological or spiritual care to patients (Slocum-Gori et al. 2011), it would be beneficial for future research to involve all members of staff who might provide such care in order to better understand the stress of providing care within palliative settings.

References

Abendroth, M. & Flannery, J. (2006). Predicting the Risk of Compassion Fatigue. *Journal of Hospice & Palliative Nursing, 8*(6), 346.

Ablett, J.R. & Jones, R.S.P. (2007). Resilience in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-Oncology, 16,* 733-740.

Athlin, E., Furåker, C., Jansson, L., & Norberg, A. (1993). Application of primary nursing within a team setting in the hospice care of cancer patients. *Cancer Nursing, 16(5),* 388-397.

Aycock, N. & Boyle, D. (2009). Interventions to manage compassion fatigue in oncology nursing. *Clinical Journal of Oncology Nursing, 13(2),* 183-191.

Bearman, M. & Dawson, P. (2013). Qualitative synthesis and systematic review in health professions education. *Medical Education, 47(3),* 252-260.

Brenner, P. R. (1997). Managing patients and families at the ending of life: Hospice assumptions, structures, and practice in response to staff stress. *Cancer Investigation, 15*(3), 257-264.

Bruneau, B. M. S., & Ellison, G. T. H. (2004). Palliative care stress in a UK community hospital: evaluation of a stress-reduction programme. *International Journal of Palliative Nursing, 10(6),* 296-304.

Burnard, P., Edwards, D., Bennett, K., Thaibah, H., Tothova, V., Baldacchino, D.,… Mytevelli, J. (2008). A comparative, longitudinal study of stress in student nurses in five countries: Albania, Brunei, the Czech Republic, Malta and Wales. *Nurse Education Today, 28*(2), 134-145.

Chang, E.M., Bidewell, J.W., Huntingdon, A.D., Daly, J., Johnson, A., Wilson, H.,…Lambert, C.E. (2007). A survey of role stress, coping and health in Australian and New Zealand hospital nurses. *International Journal of Nursing Studies, 44(8),* 1345-1362.

Cocker, F. & Joss, N. (2016). Compassion fatigue among healthcare, emergency and
community service workers: A systematic review. *International Journal of
Environmental Research & Public Health, 13(6),* pii: E618. doi:
10.3390/ijerph13060618.

Connor, S.R. (2009). *Hospice and Palliative Care: The Essential Guide.* Oxford, UK:
Taylor & Francis.

Cooper, J. & Barnett, M. (2005). Aspects of caring for dying patients which cause anxiety
to first year student nurses. *International Journal of Palliative Nursing, 11(8),* 423-
430.

Davies, B. & Oberle, K. (1990). Dimensions of the supportive role of the nurse in
palliative care. *Oncology Nursing Forum, 17,* 87-93.

Dean, R. A. (1998). Occupational stress in hospice care: Causes and coping strategies.
American Journal of Hospice and Palliative Medicine, 15(3), 151-154.

Desbiens, J.F. & Fillion, L. (2007). Coping strategies, emotional outcomes and spiritual
quality of life in palliative care nurses. *International Journal of Palliative Nursing,
13(6),* 291-300.

DiTullio, M. & MacDonald, D. (1999). The struggle for the soul of hospice: Stress, coping,
and change among hospice workers. *American Journal of Hospice and Palliative
Medicine, 16(5),* 641-655.

Dixon-Woods, M., Bonas S., Booth, A., Jones, D.R., Miller, T., Sutton, A.J.,…Young, B.
(2006). How can systematic reviews incorporate qualitative research? A critical
perspective. *Qualitative Research, 6(1),* 27-44.

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S.,…
Jones, D. (2007). Appraising qualitative research for inclusion in systematic
reviews: A quantitative and qualitative comparison of three methods. *Journal of
Health Services, Research & Policy, 12(1),* 42-47.

Dougherty, E., Pierce, B., Ma, C., Panzarella, T., Rodin, G., & Zimmermann, C. (2009). Factors Associated With Work Stress and Professional Satisfaction in Oncology Staff. *American Journal of Hospice and Palliative Medicine, 26(2),* 105-111.

Figley, C.R. (2002). Compassion fatigue: Psychotherapists' chronic lack of self care. *Journal of Clinical Psychology, 58(11),* 1433-1441.

Fillion, L., Tremblay, I., Truchon, M., Côté, D., Struthers, C.W., & Dupuis, R. (2007). Job satisfaction and emotional distress among nurses providing palliative care: Empirical evidence for an integrative occupational stress-model. *International Journal of Stress Management, 14(1),* 1-25.

Folkman, S. & Lazarus, R.S. (1988). *Ways of Coping Checklist.* Redwood City, CA: Consulting Psychologists Press, Inc.

Georges, J. J., Grypdonck, M., & Dierckx de Casterle, B. (2002). Being a palliative care nurse in an academic hospital: A qualitative study about nurses' perceptions of palliative care nursing. *Journal of Clinical Nursing, 11(6),* 785-793.

Graham, J., Ramirez, A.J., Cull, A., Finlay, I., Hoy, A., & Richards, M.A. (1996). Job stress and satisfaction among palliative physicians. *Palliative Medicine, 10(3),* 185-194.

Gray-Toft, P., & Anderson, J. G. (1981). Stress among hospital nursing staff: its causes and effects. *Social Science & Medicine, 15*(5), 639-647.

Hackett, A. & Palmer, S. (2010). An investigation into the perceived stressors for staff working in the hospice service. *International Journal of Palliative Nursing, 16(6),* 290-296.

Hackett, A., Palmer, S., & Farrants, J. (2009). Phase 1 of an investigation into the levels of stress in United Kingdom hospice services. *International Journal of Palliative Nursing, 15(2),* 66-72.

Harris, L. J. M. (2013). Caring and coping: Exploring how nurses manage workplace

stress. *Journal of Hospice & Palliative Nursing, 15(8),* 446-454.

Hawkins, A.C., Howard, R.A. & Oyebode, J.R. (2007). Stress and coping in hospice
nursing staff: The impact of attachment styles. *Psycho-Oncology, 16(6),* 563-572.

Health & Safety Executive (2016). *Work related stress, anxiety and depression statistics in
Great Britain 2016*. London, UK: Health & Safety Executive. Retrieved from
http://www.hse.gov.uk/statistics/causdis/stress/.

Help The Hospices Commission (2013). *Future Ambitions for Hospice Care: Our Mission
and Our Opportunity*. London, UK: Help The Hospices.

Higgins J, & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of
Interventions* [Version 5.1.0]. Retrieved from: www.handbook.cochrane.org.

Higginson, I. J., Calanzani, N., & Gomes, B. (2013). *Current and Future Needs for
Hospice Care: An Evidence Based Approach*. London, UK: Help The Hospices.

Keidel, G.C. (2002). Burnout and compassion fatigue among hospice caregivers. *American
Journal of Hospice & Palliative Care, 19(3),* 200-205.

Koh, M. Y. H., Chong, P. H., Neo, P. S. H., Ong, Y. J., Yong, W. C., Ong, W. Y., . . .
Hum, A. Y. M. (2015). Burnout, psychological morbidity and use of coping
mechanisms among palliative care practitioners: A multi-centre cross-sectional
study. *Palliative Medicine, 29(7),* 633-642.

Lazarus, R.S. & Folkman, S. (1984). *Stress, Appraisal & Coping.* New York, NY: Springer
Publishing.

Lees, S. & Ellis, N. (1990). The design of a stress-management programme for nursing
personnel. *Journal of Advanced Nursing, 15(8),* 946-961.

Lobb, E. A., Oldham, L., Vojkovic, S., Kristjanson, L. J., Smith, J., Brown, J. M., &
Dwyer, V. W. J. (2010). Frontline grief: The workplace support needs of
community palliative care nurses after the death of a patient. *Journal of Hospice &
Palliative Nursing, 12(4),* 225-233.

Loes van Staa, A., Visser, A., & van der Zouwe, N. (2000). Caring for caregivers: Experiences and evaluation of interventions for a palliative care team. *Patient Education and Counselling, 41,* 93-105.

Lovibond, S.H. & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scales.* (2nd. Ed.) Sydney, Australia: Psychology Foundation.

Mackereth, P. A., White, K., Cawthorn, A., & Lynch, B. (2005) Improving stressful working lives: Complementary therapies, counselling and clinical supervision for staff. *European Journal of Oncology Nursing, 9(2),* 147-154.

Macpherson, G. E. (2002). *Black's Medical Dictionary*. New York, NY: A & C Black Publishers Ltd.

Martens, M. L. (2009). A comparison of stress factors in home and inpatient hospice nurses. *Journal of Hospice & Palliative Nursing, 11(3),* 144-153.

Maslach, C. & Jackson, S.E. (1981). The measurement of experienced burnout. *Journal of Organizational Behavior, 2(2),* 99-113.

Maslach, C., Schaufeli, W. B., & Leiter, M. P. (2001). Job Burnout. *Annual Review of Psychology, 52(1),* 397-422.

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. doi:10.12968/ijpn.2010.16.5.48144

McConnell, T., O'Halloran, P., Donnelly, M., & Porter, S. (2015). Factors affecting the successful implementation and sustainability of the Liverpool Care Pathway for dying patients: A realist evaluation. *BMJ Supportive & Palliative Care, 5(1),* 70-77.

McConnell, T. & Porter, S. (2017). The experience of providing end of life care at a children's hospice: a qualitative study. *BMC Palliative Care, 16(1),* 15-20.

McConnell, T., Scott, D., & Porter, S. (2016). Healthcare staff 's experience in providing

end-of-life care to children: A mixed-method review. *Palliative Medicine, 30(10*), 905-919.

McVicar, A. (2003). Workplace stress in nursing: A literature review. *Journal of Advanced Nursing, 44(6),* 633-642.

Melvin, C. S. (2012). Professional compassion fatigue: what is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing, 18(12),* 606-611.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine, 6(7).*

Montross-Thomas, L. P., Scheiber, C., Meier, E. A., & Irwin, S. A. (2016). Personally meaningful rituals: A way to increase compassion and decrease burnout among hospice staff and volunteers. *Journal of Palliative Medicine, 19(10),* 1043-1050.

National Institute of Clinical Health & Excellence (NICE) (2004). *Improving Supportive and Palliative Care for Adults with Cancer.* London, UK: NICE.

Newton, J., & Waters, V. (2001). Community palliative care clinical nurse specialists' descriptions of stress in their work. *International Journal of Palliative Nursing, 7(11),* 531-540.

Nordgren, L., & Olsson, H. (2004). Palliative care in a coronary care unit: a qualitative study of physicians' and nurses' perceptions. *Journal of Clinical Nursing, 13(2),* 185-193.

Pace, R., Pluye, P., Bartlett, G., Macaulay, A.C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies, 49(1),* 47-53.

Payne, N. (2001). Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing, 33(3),* 396-405.

Peters, L., Cant, R., Sellick, K., O'Connor, M., Lee, S., Burney, S., & Karimi, L. (2012). Is work stress in palliative care nurses a cause for concern? A literature review. *International Journal of Palliative Nursing, 18(11),* 561-567.

Pierce, B., Dougherty, E., Panzarella, T., Le, L. W., Rodin, G., & Zimmermann, C. (2007). Staff stress, work satisfaction, and death attitudes on an oncology palliative care unit, and on a medical and radiation oncology inpatient unit. *Journal of Palliative Care, 23(1),* 32-39.

Plante, A., & Bouchard, L. (1996). Occupational stress, burnout, and professional support in nurses working with dying patients. *Omega, 32(2),* 93-109.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F,… Rousseau, M. C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. Retrieved from: http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/84371689/MMA T%202011%20criteria%20and%20tutorial%202011-06-29updated2014.08.21.pdf

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. In. Unpublished Report, Results of an ESRC funded research project, University of Lancaster, UK.

Power, K. G. & Sharp, G. R. (1988). A comparison of sources of nursing stress and job satisfaction among mental handicap and hospice nursing staff. *Journal of Advanced Nursing, 13(6),* 726-732.

Ramirez, A.J., Graham, J., Richards, M.A., Cull, A., Gregory, W.M., Leaning, M.S.,…Timothy, A.R. (1995). Burnout and psychiatric disorder among cancer clinicians. *British Journal of Cancer, 71(6),* 1263-1269.

Rittman, M., Paige, P., Rivera, J., Sutphin, L., & Godown, I. (1997). Phenomenological study of nurses caring for dying patients. *Cancer Nursing, 20(2),* 115-119.

Ryan, R. (2013). *Cochrane Consumers and Communication Review Group: Data Synthesis and Analysis*. Retrieves from:

http://cccrg.cochrane.org/sites/cccrg.cochrane.org/files/public/uploads/Analysis.pdf

Shimizu, T., Mizoue, T., Kubota, S., Mishima, N., & Nagata, S. (2003). Relationship between burnout and communication skill training among Japanese hospital nurses: A pilot study. *Journal of Occupational Health, 45(3),* 185-190.

Showalter, S.E. (2010). Compassion fatigue: What is it? Why does it matter? Recognizing the symptoms, acknowledging the impact, developing the tools to prevent compassion fatigue, and strengthen the professional already suffering from the effects. *American Journal of Hospice & Palliative Care, 27(4),* 239-242.

Slocum-Gori, S., Hemsworth, D., Chan, W. W. Y., Carson, A., & Kazanjian, A. (2013). Understanding Compassion Satisfaction, Compassion Fatigue and Burnout: A survey of the hospice palliative care workforce. *Palliative Medicine, 27(2),* 172-178.

Stamm, B. H. (2002). Measuring compassion satisfaction as well as fatigue: Developmental history of the compassion satisfaction and fatigue test. In C.R. Figley (Ed). *Treating compassion fatigue*, (pp 107-119). New York, NY: Brunner-Routledge.

Stoddard, S. (1978). *The Hospice Movement: A Better Way of Caring for the Dying*. London, UK: Vintage Books.

Taylor B., Glass, N., McFarlane J., & Stirling C. (1997). Palliative nurses' perceptions of the nature and effects of their work. *International Journal of Palliative Nursing, 3(5),* 253-258.

Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: Providing the research evidence for public health nursing interventions. *Worldviews on Evidence-Based Nursing, 1(3),* 176-

184.

Tunnah, K., Jones, A., & Johnstone, R. (2012). Stress in hospice at home nurses: a
qualitative study of their experiences of their work and wellbeing. *International
Journal of Palliative Nursing, 18(6),* 283-289.

Tyler, P. A. & Ellison, R. N. (1994) Sources of stress and psychological well-being in
high-dependency nursing. *Journal of Advanced Nursing, 19(3),* 469-476.

Vachon, M. L. S. (1995). Staff stress in hospice/palliative care: A review. *Palliative
Medicine, 9(2),* 91-122.

Vachon, M.L.S. (1998) Caring for the caregiver in oncology and palliative care. *Seminars
in Oncology Nursing, 14(2),* 152–157.

Viswesvaran, C., Sanchez, J.I., & Fisher, J. (1999). The role of social support in the
process of work stress: A meta-analysis. *Journal of Vocational Behavior, 54(2),*
314-334.

Wall, T. D., Bolden, R. I., Borrill, C. S., Carter, A. J., Golya, D. A., Hardy, G. E., . . .
West, M. A. (1997). Minor psychiatric disorder in NHS trust staff: Occupational
and gender differences. *British Journal of Psychiatry, 171*, 519-523.

Wallerstedt, B. & Andershed, B. (2007). Caring for dying patients outside special
palliative care settings: Experiences from a nursing perspective. *Scandinavian
Journal of Caring Sciences, 21(1),* 32-40.

Wenzel, J., Shaha, M., Klimmek, R., & Krumm, S. (2011). Working Through Grief and
Loss: Oncology Nurses' Perspectives on Professional Bereavement. *Oncology
Nursing Forum, 38(4),* 272-282.

Wilkes, L.M. & Beale, B. (2001). Palliative care at home: Stress for nurses in urban and
rural New South Wales, Australia. *International Journal of Nursing Practice, 7(5),*
306-313.

Wilkes, L.M., Beale, B., Hall, E., Rees, E., Watts, B., & Denne, C. (1998). Community

nurses' descriptions of stress when caring in the home. *International Journal of Palliative Nursing, 4(1),* 14-20.

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 (WHO) (2009). *WHO Definition of Palliative Care*. Geneva, Switzerland: WHO. Retrieved from http://www.who.int/cancer/palliative/definition/en/.

Chapter 2.

Bridging Chapter

Bridging Chapter

The systematic review aims to understand the stressors of wider care staff who provide palliative services, while the empirical paper explores the experiences of the varied care staff in children's hospices supporting families after the death of an infant. Results of the systematic review indicated that levels of stress varied when looking at multiple staff affiliations together, and the settings in which palliative care was given could impact on the perceptions of stress. The systematic review highlighted typical stressors which included organisational difficulties, interpersonal relationships and difficulties related to patient and family care. A number of coping strategies were also identified within the included papers, and emphasised the importance of staff support in managing the difficulties of palliative care. The review also emphasised the importance of self-care and reflective practices as coping mechanisms.

As noted, the experiences of stress in nurses who provide palliative care for adults is well documented (for reviews, see: Peters et al., 2012; Vachon, 1995). More recently, the focus of research has expanded to understand the specific experiences and stressors of working within paediatric palliative care (for reviews, see: Barnes et al., 2001; McConnell et al., 2016). Therefore, it was presumed that stressors would be identified within the qualitative study, specifically related to this specialist care pathway, which will now be explained.

'Cold' Facilities and the Hospice Context

It is necessary to first explain the context of 'cold' facilities in bereavement support and the specific facilities provided at the hospices investigated. 'Cold' facilities refer to the use of specific rooms, refrigerated cots and cooling mats for a family to use whilst in the hospice or in at-home hospice care after an infant has died. The rooms in the hospices involved in this research are in separate wings, and enable family to have unrestricted

access to their infant's body throughout the period after death until the time of the funeral. The time period varies family by family, and is decided at the discretion of the hospice team on a day by day basis depending on the condition of the body. This can be for up to two weeks.

The chilled cots and mats are provided by FlexMort, and are branded CuddleCots™. The CuddleCots™ are discrete units with a cooling box which omits little noise while keeping the cots chilled. The mats are small units which can be placed on a normal bed, to allow the family the opportunity to lie with the infant's body should they wish to. The mat can be placed under the bed sheet for discretion and wires lead off to a cooling box on the floor. This portable equipment also allows family the option of keeping the infant's body at home until the funeral, and staff then provide at-home hospice support to the family.

Before CuddleCots™ were available to the regional hospices approximately seven years ago, this opportunity to stay with the infant's body was provided by having cooling units in the dedicated bereavement wings which were kept under 10°C for the condition of the infant's body to be maintained. Staff noted that previously 'cold bedrooms' were uncomfortable for families to stay in due to having to be kept at this low temperature, and the advent of FlexMort's portable equipment has meant the hospices have seen an increase in referrals for the service within the neonatal care pathway. The cooling units continue to be used as a back-up in case the CuddleCot™ malfunctions.

The neonatal care pathway at these hospices involves referral from the local Neonatal Intensive Care Units (NICU). These referrals can occur before the infant's death if the loss is expected, though these also occur after death in the case of unexpected deaths such as stillbirths or deaths resulting from birth traumas. Staff from the hospices endeavour to meet families at the NICU if appropriate and explain the services available through the

hospices; namely either in hospice or at-home hospice support. They offer both practical and emotional support to family, and facilitate funeral planning with external funeral directors.

Care is provided by the Wellbeing Teams and Care Teams within the hospices involved in the study; Wellbeing Teams consist primarily of counsellors, art therapists and play therapists whilst Care Teams consist primarily of nurses and nursing assistants. In recent years, all bereavement support to the family would be provided by the Wellbeing Teams and would also include 'Journey Work' (before death) and 'Memory Work' (after death). These pieces of work involve creating mementos for the family through gathering hair clippings, hand and foot prints and creating silver casts. The family would be given the choice of either assisting in the 'Journey' and 'Memory Work' or having a member of staff do this for them. If completing the memory work without the family present, this would involve two members of staff working together to hold the infant's body in order to make the prints and casts.

The Care Teams would be responsible for the nursing care as the infant approached end-of-life, if a referral was made to the hospice before death, and would then care for the deceased body, primarily. This involves regular checking of the body for signs of deterioration and decay. They would also provide practical care for families. In early 2017, the hospices adapted the way they delivered care by creating a 'universal system'; this meant that all staff within both the Wellbeing Teams and Care Teams could be responsible for any aspect of care for the family and the deceased body. Staff from both teams would also help with funeral arrangements and facilitate services such as coffin decoration for the infant.

Evidence base for 'cold' facilities

FlexMort report that their CuddleCots™ are used in over 95% of hospitals in the UK (FlexMort, 2017), however there are no figures provided for the number of children's hospices in the UK who use CuddleCots to provide 'cold' services for families who have lost an infant. However, regional hospice staff report there is increasing use in hospices nationally. There has been no research to date exploring portable 'cold' facilities such as the CuddleCot™, and to date only two studies have been published which investigate the use of 'cold' facilities more generally (Davies, 2005; Forrester, 2008). Davies (2005) conducted a questionnaire study asking parents about their experiences using 'cold' bedrooms after the death of a child, and Forrester (2008) compared experiences of mothers who used 'cold' bedrooms against mothers who did not after the death of a child. Neither study looked at the staff experiences of providing such specialist care, and therefore it is important for research to better understand the unique and specialist services being provided to families after the death of an infant specifically.

McConnell and Porter (2017) identified that the complexity of navigating different types of care alongside each other in the paediatric hospice workplace, typically including extended respite care and providing bereavement support, was a challenge for staff to navigate. Within the hospices being investigated, this complexity is also navigated alongside the additional pathway wherein staff work alongside (and often provide care for) the deceased bodies of infants. It was presumed that some of the experiences of conducting this part of the work would be difficult to make sense of, particularly in light of the widely accepted emotional demands of palliative care (Hill, Dempster, Donnelly & McCorry, 2016) and societal views on death and dead bodies.

Context of Societal Views

Western societies are generally thought of as being in a state of denial regarding death (Connor, 2009; Stevens, 2009; Zimmerman, 2012), with the topic being generally

avoided in conversation and regarded as morbid (Zimmerman & Rodin, 2004). In the last

century, death has evolved from being a process that happens in the home to one which

happens in external institutions (Connor, 2009), with the discussion and planning for death

being a process that was previously routine for families and communities and is now

viewed more as a medical failure (Kellehear, 2005). Shucksmith, Carlebach and Whittaker

(2013) surveyed social attitudes in the British population in 2012 and found that although

the majority of people (70%) felt comfortable talking about death, only one third had

actually discussed any aspect of planning for their own deaths with anyone.

It has been noted that there are vast cultural and spiritual differences in how people

treat death and specifically the care of dead bodies. Becker (1973) suggested that a primary

obligation of a culture is to protect a people from knowledge and fear of death, and this is

formed by shared meaning making and beliefs often rooted in religious beliefs. Quested

and Rudge (2003) note that practices vary worldwide in how we view dead bodies, from

funeral pyres in India to second burials in Indonesia to the widely used embalming

methods in the USA which protect people from ever witnessing decay. They note that in

the UK, nursing care for dead bodies, which is known as Last Offices, are a series of

practical tasks largely invisible to other healthcare professionals, which is reflective of how

we as a society view and avoid death (Lawler, 1991). 'Death anxiety' is defined as the

feelings of apprehension that accompany the awareness of death (Abdel-Kahlek, 2005) and

the knowledge of its inevitability is acknowledged as a universal human dilemma (Lehto &

Stein, 2009). A way of managing the dilemma of self-preservation alongside the

knowledge of an inevitable death has been conceptualised as the Terror Management

Theory (Greenberg, Pyszczynski, & Solomon, 1986), which posits that humans allay this

terror by embracing cultural values (or religious systems) that provide meaning and value

to life. Cultural worldviews allow people to distance themselves from death by offering

either a literal or symbolic transcendence, by way of either an afterlife or by giving one's

life eternal meaning (Bassett, 2007). Terror Management Theory would suggest that Western cultures protect people from death anxiety by allowing people to see the world as safe and within their control, and therefore making death something that is avoidable through "vigilance and good living" (Bassett, 2007; p. 729).

In contrast to wider societal perspectives on death, hospice care is noted to be 'care provided to people facing death by people unafraid to face death (Connor, 2009, p. 1) and reflects a community of people dedicated to relieving suffering and fostering opportunities for growth at the end-of-life. In contrast with the general population, hospice staff are confronted by death on a regular basis and it is presumed that staff who choose to work in this area are comfortable with the idea of death and dying (Payne, Dean & Kalus, 1998). Zimmerman (2012) noted that the hospice environment not only socialises patients and families to viewing death in an accepting way which benefits those using the service, but also benefits the staff and organisation. In their study comparing death anxiety in hospice and emergency nurses, Payne et al. (1998) found that hospice nurses showed less fear of death and more acceptance than emergency nurses. However, even within hospice care where death and dying are faced in an accepting way, the idea of working in an environment where an infant's dead body is present for the duration of a family's involvement with the staff appears a uniquely different situation. Staff will not only be facing death in an abstract way, but will be seeing death in a literal, physical sense and working alongside death in providing care for a grieving family. The experiences of these staff and the sense they make of this part of their work alongside their wider roles in children's palliative care is an area not yet explored in the literature, and the empirical paper aims to begin addressing this topic.

Chapter 3.

Empirical paper prepared for submission to: Qualitative Health Research

What are the experiences of staff at children's hospices who use cold facilities to care for families after the death of an infant? A qualitative study.

Meghan J. Waugh[a], Kiki Mastroyannopoulou[b]*, and Paul Fisher[c]

[abc]*Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom*

*Correspondence concerning this article should be addressed to Kiki Mastroyannopoulou, Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom.

Email: k.mastroyannopoulou@uea.ac.uk

Total word count: 8698

Word count excluding abstract and references: 7403

Abstract

Children's hospices have expanded to include 'cold' facilities enabling an infant to remain in the hospice after death until the time of funeral. There is a paucity of research exploring the use of 'cold' facilities in supporting families after a child has died, and none after the death of an infant. Additionally, research has not explored the experiences of staff caring for these deceased infants and their families. To address this, semi-structured interviews were conducted with staff from a UK hospice organisation. A thematic analysis identified two key themes (challenges within the pathway and ways that challenges are met) and 12 subthemes. Challenge subthemes included relationships with families, the unexpected, circumstances of death, passivity, associations to self, and questioning of self. Subthemes of the ways challenges are met were: active reflection, protective strategies, experience, perceptions of work, personal characteristics and organisational structures. Directions for further research and practice implications are discussed.

Word count: 150

Introduction

In the UK, 4,392 stillbirth and infant deaths were reported in 2015 (Manktelow et al., 2017), with an average of 2,500 infants dying each year in England and Wales (Office for National Statistics, 2017). It is reported that around 98% of infant deaths occur in hospital (ACT, 2009). Palliative care, which has developed to encompass care promoting quality of life in life-limiting conditions and at end-of-life, is typically delivered in a variety of settings including inpatient units, hospices and at-home care provided by hospices. Hospice care involves a wide range of support to people living with life-limiting or life-threatening conditions and their families, and helping people through the challenges they face (Help the Hospices, 2013). Palliative care specifically for infants within the NHS is typically offered from 28 days after birth, which leaves the neonate (0-4 weeks) typically being cared for in a hospital environment until death (ACT, 2009; Moro, Kavanaugh, Okuno-Jones & Vankleef, 2006). There is a growing shift for children's hospices to offer services where parents can bring their infant either before or shortly after their death to rest at the hospice with the family until the time of the funeral. The length of stay can range from one day to over two weeks, depending on the condition of the infant's body, the family needs and views of the hospice staff. This has historically been offered through the use of 'cold bedrooms', which refers to a room or suite of rooms kept under 10° C for the family and infant to stay in after the infant's death.

In recent years, this provision of care has evolved with the advent of chilled cots (FlexMort CuddleCots™) which have been installed in a large number of Neonatal Intensive Care Units (NICU) and a small but increasing number of children's hospices in the UK. This has meant that families are offered the chance to spend more time with their infant after death while in hospital, though time and space are normally limited. A hospice organisation in England have adapted their cold facilities to include CuddleCots™ for use

in hospice and at home, as well as cooling mats to allow families to rest by the infant's body. This care provision occurs in separated wings of the hospices, to give families privacy to grieve, and for staff to provide physical, practical and emotional support to the family. This organisation has a specific neonatal care pathway in liaison with local hospitals to identify and offer services to families who may benefit from use of the 'cold' facilities at the hospice.

To date, only two published studies have looked at the use of cold facilities in caring for the bereaved and their deceased children (Davies, 2005; Forrester, 2008), neither of which focused on infants. Additionally, no studies have investigated experiences of staff members who provide this care alongside their primary roles in children's palliative care. A large body of research exists looking at nursing stress and coping in palliative care for adults (for reviews see: Vachon, 1995; Peters et al., 2012), with a smaller subset of studies looking at the experiences of working within children's palliative care (Barnes, 2001; Gold, 1997; Lee & Dupree, 2008; McCloskey & Taggart, 2010; McConnell & Porter, 2017; Woolley, Stein, Forrest & Baum, 1989). Findings suggest that the stress nurses experience in adult palliative care is less than that in other specialties (Vachon, 1997; Hackett, Palmer & Farrants, 2009; Payne, 2001); however, it has been noted that palliative care for children differs both in the physical conditions worked with and the ethos of care offered to children and families (ACT, 2009) and working with younger patients can be perceived as a particular challenge (Hackett & Palmer, 2010). It is also unique in the length of relationships that staff will develop with children and families, which can range from a few days to years. In paediatric oncology nurses, Kushnir et al. (1997) found that often stress was associated with the death of patients that nurses had developed close relationships with, and reported grief and feelings of helplessness as a result. This experience of stress was particularly high when a death was unexpected. Romesberg (2004) describes the experience of caring for grieving parents of infants in a NICU, and the

intense emotions that healthcare professionals are exposed to when supporting families through the early days of grief.

It has been noted that work within paediatric palliative care can be exhausting (Gold, 1997) and studies have found that the death of a child or infant can result in emotional distress for staff in healthcare services (Edi, Osage & Evans, 2005; Kaunonen, Tarkka, Hautamaki & Paunonen, 2000; Lee & Dupree, 2008; Morgan, 2009; Plante & Cyr, 2011). Vachon and Pakes (1984) found that staff who identified more with patients or families were more susceptible to stress after the death of a child. It also appears that stress in paediatric palliative care is often related to the relationships between staff members and the workplace environment (Barnes, 2001). However, it is important to note that studies looking at the impact of a child's death on staff have primarily focused on staff where curative solutions would be the primary focus of the work, such as within intensive care settings. Literature on providing end-of-life care to children in hospice settings is incredibly limited, but McConnell and Porter (2017) noted that staff felt well supported within the hospice and found the work rewarding, despite facing challenges in the role. Challenges included symptom management, communication with families and managing their own grief responses when a child died.

Within children's hospices offering families the opportunity to spend prolonged time with their infant after death, staff provide care to families recently bereaved alongside their work aimed at enhancing the quality of life for children with life-limiting conditions and their families. This balance between respite care and end-of-life care has been found to be challenging within the paediatric hospice environment (McConnell & Porter, 2017), therefore it is particularly interesting to explore how this balance is navigated when working with or around an infant's dead body.

Aim

The experiences of staff in children's hospices supporting families using cold facilities after the death of an infant is presumably a unique challenge, and this study aims to explore how staff navigate that complexity alongside their usual roles. This study aims to not only add to the evidence base regarding the use of cold facilities and neonatal end-of-life care, but will also explore issues around the emotional impact on staff of taking on this type of work. This study will therefore set out to answer the following questions in relation to the cold facilities and support provisions available:

1) What are the experiences of hospice staff who support families after the death of an infant?

2) How do staff make sense of working in an environment where an infant's deceased body may be present, when this aspect of care is not a regular feature within their full-time role within paediatric palliative care?

3) What do staff who support families using the cold facilities, perceive their own wellbeing needs to be in carrying out this work?

Method

This study utilised a qualitative approach to allow for an in depth exploration of staff's experiences, which was conducted through semi-structured interviews to enable a free flowing, conversational style (Denzin & Lincoln, 2011).

Participants and Setting

This study recruited staff members from the Care Teams and Wellbeing Teams within a small hospice organisation in eastern England, who provide specialist palliative care services through three hospices in the region. Services include planned and emergency respite breaks, symptom management, family support, end-of-life care and bereavement

support. The hospices are linked to external funeral directors, and also local hospitals who offer referrals to families when infants have either died or are approaching end-of-life. The organisation provides services both within their hospices and in-home.

Participants were recruited from two hospices within the organisation using purposive sampling from the available members of staff who met the inclusion criteria. The criteria were that staff members: (a) identified themselves as providing a significant supportive role in working with families after the loss of an infant, (b) were involved in supporting families after the loss of an infant for the duration of their stay at the hospice, and (c) were in their job roles for at least 1 year and had supported at least two families through use of the cold facilities. This length of time was decided to ensure that staff had multiple experiences in caring for families within this pathway The first author attended staff meetings for the Care Teams (consisting primarily of nurses) and Wellbeing Teams (primarily counsellors and art therapists) to discuss the study, provide literature and expression of interest forms and answer questions about the research. Managerial staff unaffiliated with the teams also emailed staff attaching the study information on behalf of the researcher, with details on how to contact the researcher should staff be interested in taking part.

Seven semi-structured face-to-face interviews were carried out within private rooms in the hospices, each lasting approximately 60 minutes. Staff were given the option to choose the location of their interviews, and all chose to be interviewed within the hospice. Interviews were conducted by the primary researcher, M.W., an experienced female researcher with no prior relationship to the participants. Professional affiliations of the participants were nurses (n=1), counsellors (n=4), and managers from a nursing background (n=2).

An interview guide was developed through consultation with experienced members of the hospice organisation who had previous experience in conducting qualitative research. The interview guide was developed from the research objectives, with prompts related to key themes from relevant literature reviews (Barnes, 2001; McConnell, Scott & Porter, 2016; Peters et al., 2012). Final interview questions were decided within the research team and with approval from the hospice organisation.

Ethical Considerations

Ethical approval was granted from University of East Anglia's Faculty of Medicine & Health Sciences Research & Ethics Committee. Approval was also granted from the hospice's Board of Trustees to undertake the research within the organisation. All participants provided their written, informed consent.

Data Analysis

Interviews were audio recorded and transcribed verbatim by the primary researcher, and a sample of interviews were checked for accuracy by the primary research supervisor (K.M.) and secondary research supervisor (P.F.). Three participants undertook member checking (Seale, 1999) to ensure the transcripts were an accurate reflection of the words said and their intent. Transcripts were analysed using the six-step process of thematic analysis operationalised by Braun and Clarke (2006). Transcripts were coded line by line for relevance to the research questions, and codes were arranged into themes and subthemes by M.W. A random selection of transcripts were examined by K.M. and codes, themes and subthemes were discussed, with consensus reached to validate the themes. The initial thematic analysis was confirmed by two participants.

A social constructionist stance was taken with an emphasis on contextualism. This research supposes that sense is made through the social processes one is a part of (Braun &

Clarke, 2013; Tebes, 2005), and that there is a relationship between a person's account of reality and the context in which they exist in (Madill, Jordan & Shirley, 2000; Tebes, 2005). This extends to the context of the researcher, and the context of the research process. A reflective journal was used throughout data collection and analysis to record assumptions, impressions, decision making and the reasoning behind decisions.

<div align="center">

Results

</div>

Seven individual interviews were conducted with participants who were counsellors, nurses or nursing managers. Their length of employment with the organisation ranged from seven to 26 years, with a mean length of service of 11.5 years. All staff had spent their professional careers in caring professions, either in hospice settings, acute inpatient settings or social care.

It is important to note that all staff interviewed were positive about their experiences of work, and did not explicitly report stressful experiences. All staff talked about the rewarding nature of palliative care, and were primarily positive in their reflections about the organisation. Questions were aimed at identifying experiences that resonated with staff, and how sense was made of them. The thematic analysis identified two main themes, with 12 subthemes (Figure 1).

Challenges Within the Pathway

This theme encompasses the aspects of staff's work within the neonatal pathway which at they found difficult to navigate at times. It should be noted that the staff did not seem to view their work as challenging overall, but there were commonalities to the unique aspects of the pathway that required staff to employ strategies to manage.
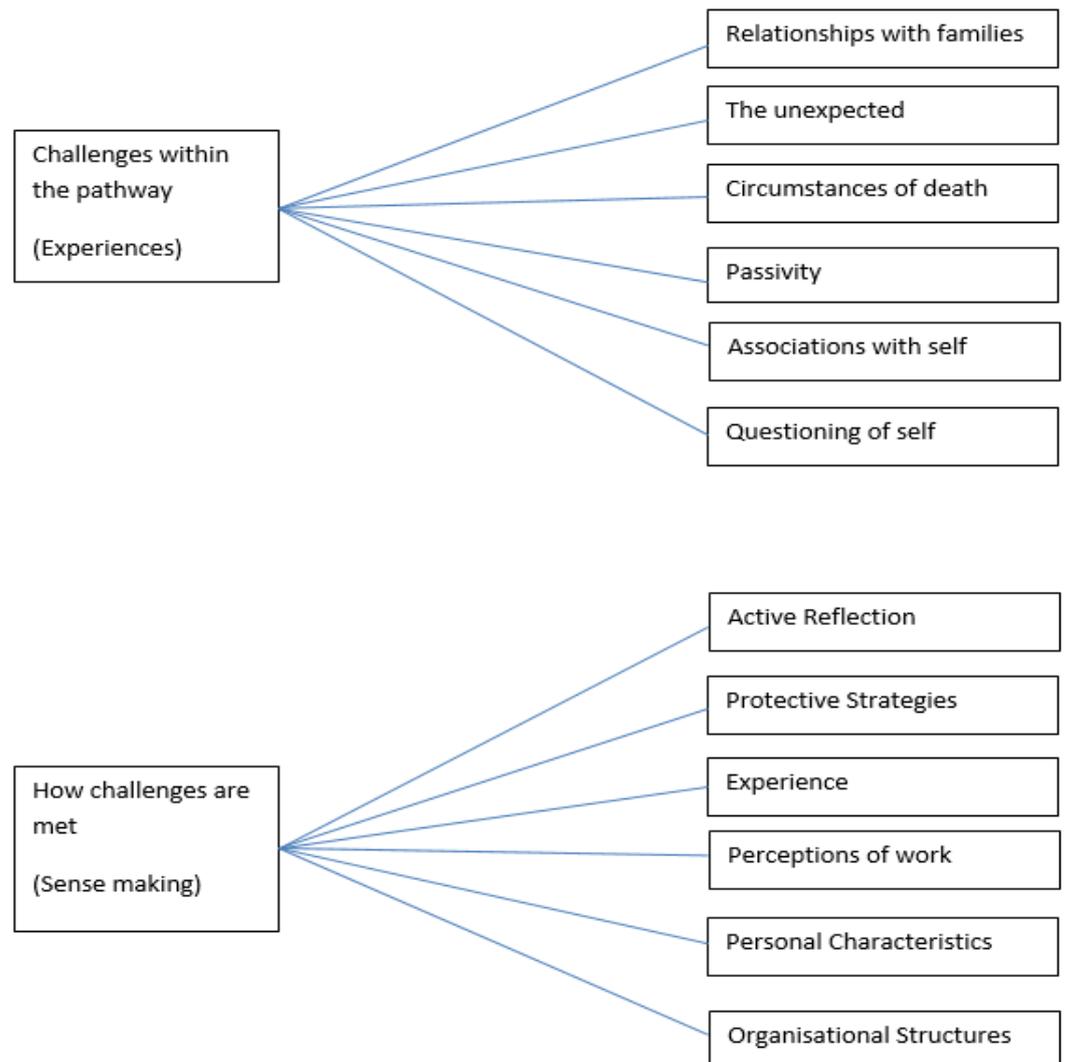
Figure 1: Map of themes and subthemes

Relationships with families. Staff spoke about needing to build relationships quickly with bereaved families, and this at times being a challenge either on a professional or personal level. Some staff found that only knowing the family for a number of days meant they were less affected emotionally than they were when children had died who they had known for lengthy periods of time. Staff noted that a longer relationship might help them feel confident in knowing how to respond to the family, but could leave staff feeling the sadness of loss more significantly.

"I think there's, well there's an element of you, you know a lot more isn't there. If I know a family and I've worked with them through um approaching death, I'll know their history I'll know maybe their coping mechanisms. …. So you get more of an attachment or you get more of a therapeutic relationship with somebody, whereas if I'm holding a family for a colleague… I might not have all that background history that would then lead me to feel differently."

"It's easier and it's harder. So the longer the journey you've had with them, the easier it is at the very end because you kind of have got a little bit more… to work with. You've got more words. You've got more history. So that helps. So in that way it's easier, in other ways it's harder because you've had this journey so you've built up a level of… relationship's the wrong word isn't it, but you know you've built up a level of… knowledge that can now make you share a little bit in some of the grief they're going through."

The unexpected. Staff reflected on how first experiences of any kind within this pathway were the most challenging, when they were unsure of what they would see or how the family might respond. This was often related to the shorter relationships with families through this care pathway.

"I think sometimes I might be caught unaware by a parent's response if they do something that I hadn't seen before. I might process that a bit differently at the beginning."

"And I'd say probably after three, ya know, maybe when I've responded at least three times I think, I then found a comfortable place."

Circumstances of death. Staff shared how, particularly early on in their careers, it was a challenge to see full-term babies who had died. It was easier for staff to process the

loss of life when the infant had been particularly ill or was very premature. Staff talked about it being easier for them emotionally to support a family when the infant could not have survived or this was an expected loss, but there was something powerful in seeing a 'perfect baby' and the loss of potential.

> *"But when you get a hunk of the chunk of a 40-week baby, that should have been everything… that does feel very sad."*

> *"But I feel, I feel their loss of hope. And they're everything and you've just delivered this baby and they're dead."*

Passivity. Staff talked about the challenges of having a passive role when supporting families, and being left with their thoughts and the strong emotions of the family in the room. Staff talked about the sadness being moving and powerful when you did not have practical aspects of care to attend to.

> *"You know where you sit and passively watch something. Um, yeah, that was much, much, much harder than doing what I needed to do. Because as a, when you're there as a professional, you've got all the things going in your head don't you, 'I need to be doing this, I need to be mindful of this, what's mum's response, is this okay, I need to contain that'. Um, when you're sat watching, you don't have that so you just have those emotions of that moment."*

Associations with self. Staff reported that supporting families could be a challenge when the loss made them think of people in their own lives. This could be when an infant reminded them of their own, or the babies of extended family or friends. The association to self was a challenge faced in other aspects of paediatric palliative care, but was especially present for the neonatal pathway.

"Sometimes a loss will sort of bring in your greatest fear, ya know, your loss of your own child sometimes."

"I really don't think it would be possible [to work] *if you drew too many links to yourself, and for those nurses that have babies and then actually leave palliative care, I think it's for that very reason. I think it's because they know they can't make that distinction."*

Questioning of self. Staff repeatedly spoke about how experiences of caring for deceased infants and their families had led them to question themselves and their responses over time. Staff talked about wondering what it meant to be able to do the work they do, and often questioned their emotional responses. At times this would present a challenge in how this made them question their own motives or views, and could limit perceptions of confidence in their abilities.

"So then it makes me sort of reflect on who I am and think actually 'should I find this harder than I do?' – and it has been a little bit of a battle over the years, to sort of be like 'actually no, it is just being a professional'."

"Where before, I think I was quite shocked by my response... So for me I question whether I was bringing a judgement into what I was finding more difficult."

In questioning themselves, staff would often talk about an awareness of how outsiders saw the work and what that meant for them as people.

"Whereas if you try to tell someone an experience you've just had and you go 'how can we make this more positive', they'd be like 'what are you even thinking about, it's wrong, it's awful', they can't get there. But it's because they're not living it are they, day in day out, at work."

How Challenges Are Met

This theme incorporates the various ways that staff appeared to ameliorate the challenges they faced within the neonatal pathway. Processes encompassed cognitive strategies, external coping mechanisms and structures utilised within the hospice organisation.

Active reflection. Staff shared the importance of reflecting on and being aware of their own emotional responses; they talked about the sadness and pain of the families, and how they might be moved by particular experiences. For the majority of staff, being able to identify why something had triggered an emotional response in them was enough to resolve the situation internally.

> *"I was in the car park on my own, and I was in floods of tears. And I've done that so many times, so it was like 'what was different, what was different about this that made that so emotional for me?'"*

If this process of emotional awareness had not led to resolution, this reflection then highlighted the need to address it through one of the avenues available in hospice (e.g. peer support, clinical supervision or counselling support).

> *"That did something to me and I'm not really quite sure why I found it so uncomfortable, but I did. So I will bring that [to supervision].. Because I want to know kind of what it is, why was it, so that if I'm in that situation again, I've got more of an awareness about myself."*

Staff also talked about this self-awareness and questioning leading to developing more self-compassionate strategies.

"I recognise it and I'm allowed that. So I kind of give myself... 'okay, what... okay, it's fine, it's fine to feel you're upset about this.'"

Protective strategies. Staff talked about a number of conscious processes used to keep a sense of emotional distance. These included actively reminding themselves that the death was not happening to them and this was not their pain.

"It's not me. It's not my life, it's not my war. It's not happened to me. So, whilst on one hand that sounds really heartless, it's actually really restorative. Because this isn't my life, ya know."

Staff talked about the importance of the job being separate to the rest of their lives, and the importance of maintaining good boundaries.

"I've got a balance outside of here and I think work... this is a job where I've been able to leave the job at the end of the day and know that, that any task will be delegated to somebody else. So I don't have to take that home internally as well."

"Life balance as well. I think that's important. I think if my job had felt like my life, I think that could be very different."

This was done through a combination of immersion in family life and outside interests, and conscious compartmentalising and boundary setting. Staff talked about hobbies such as exercise and looking after their own children which meant they kept work and home lives separate. Some staff talked about strategies they used if they 'took a family home' with them to stop from thinking about it too much.

"So I am aware when I've gone home with something, and I will write it down. If I write it down, I put it in a book, I don't have to think 'I need to do something about that when I go back to work', or 'I don't want to forget that'. I just have a notebook

and I will put in whatever it is and close the book and that's it. I don't have to think

about it."

Staff suggested that maintaining a boundary between their professional and personal lives might also be helped by not feeling able to share their work with others outside of the hospice. As well as respecting confidentiality, staff also felt this was about protecting loved ones from experiences that might be difficult to hear about.

"But people don't… want to know or need to know, you want to protect them from

it."

Personal characteristics. Though there were no specific commonalities to the characteristics staff identified as enabling them to meet the challenges faced, there was a sense from each staff member that they felt there was something inherent to them as people that enabled them to work in this unique area of hospice care. Characteristics that emerged were often around resilience, robustness, feeling secure in themselves, and confident in their skills.

"I just trust in… the process… and being myself. I wouldn't be worried about…

God it sounds really cocky but I'm not being cocky at all, absolutely so not,

because I've really mucked up sometimes… but I would feel confident to respond to

any situation."

Staff also talked about challenges at work being opportunities to learn and improve practice, and ensure that they were able to 'get things right' for the family.

"When I've thought, 'could I have done something better? Could I have made a

different decision?' or 'could I have responded differently at that point?'. That,

they're probably the ones where I sort of think 'mmm, could there be a gap'."

Experience. Through processes of self-reflection, staff talked about their years of experience enabling them to continue working effectively. Staff spoke about 'firsts' being challenging in the beginning of their work (i.e. first times witnessing a death, or holding a body to create casts of footprints), but through increased experience staff have fewer firsts and therefore perceive fewer challenges over time. Experience and self-reflection have also enabled staff to be more aware of their needs, and feel more assertive in getting needs met at work.

> *"I think you've gone past that when you're doing it all the time, it's not that you don't think it's tough, or wrong, or awful, because you do. But I think you now start having more of an analytical mind about it."*

> *"That was quite early on into my career as well so I wasn't as good at vocalising what I needed then, as well as I am now."*

Staff also talked about how experience enabled them to use their self-awareness to keep more emotional distance from the loss of an infant.

> *"I used to do it but I don't do it anymore. But the kind of 'what ifs', the 'what should they be doing' or that sort of bit. All of the bits that they wouldn't be able to do. Those sorts of things, I used to do. I don't do that anymore.... Yeah, so it's those emotions. I don't know. I can take a step back from them, and if I choose to step into them, my job becomes harder. Um, and I used to... wander into them and not realise I was there... So you just stop yourself. Walk back out again."*

Perceptions of work. Staff talked about cold facilities being valuable for the families they support, as well as an important part of the process of families accepting loss. Staff talked about how seeing changes to the infant's body was helpful for families to accept loss, particularly when it was unexpected.

"I think it can be really healthy. Because it promotes that acceptance, it promotes the saying goodbye, the natural detaching and understanding and stepping back."

"I think that's part of the bit that their baby is cold. It, ya know, the baby is changing. They can see them deteriorating."

Staff shared how they rewarding it felt to facilitate memory making and bonding after an infant had died.

"So you could actually have a night with your baby which you won't have had in the intensive care unit. You'd have been in the same room, you'll never have been able to lay on a bed with them. Which is part of that memory making, and we've realised that for neonates, even neonates who have had a relatively long neonatal journey, a lot of what they want to do, take the baby for a walk in a pram, lay in their bed... read a story, those sorts of things, are the memories they're building after they've died. But actually what really held them together long term."

This sense that they are helping to move a family through loss seemed to protect staff against some of the emotional sadness, and staff reported feeling rewarded. Staff talked about loving their work and feeling privileged to be able to do meaningful work for families.

"I feel quite privileged because I hear that reflection back. So I hear what they see, and get a real appreciation of, 'wow that's so important'. Ya know? There's a real learning in that. It's great, it's a really privileged position to be in so that you can then keep this wheel turning for other families and try and make it be as good as possible."

"You do see them. And that's in Memory Day, in 5 years' time, you'll see them, you'll look at them and you'll smile and you'll think 'they are rebuilding their life'. That's lovely."

"It's fulfilling; I think that's a better word. And that's, that's good for yourself, your sense of self, and that's quite supportive of your own emotional resilience if you can come away feeling, ya know 'I've done something that's really helpful at a time where it's really needed'. I think that we're actually lucky in this role that we're doing that so often."

Organisational structures. Staff talked about the value of peer support and clinical supervision; though it also appears that there is an appreciation of the supportive culture within the work environment which sustains staff through difficulties. They talked about feeling supported in expressing difficult emotions in debriefs and supervision, and able to talk to peers about things they have done or seen in order to help process their experiences.

"There is the support network here. I'm working with a resilient bunch as well who support each other and that's perhaps why people are able to be here a long time, because it's a supportive environment."

"Um but it's a chance to make sense and to be heard, and to just stop for you. Just to stop for me and actually, for somebody else to… to be the receiver of that information. And either try and make sense of it, because actually it could be that I haven't made a connection myself and one of my colleagues would say 'do you think it's this?' and it could be 'ah yeah, it could be, I bet that's why it's making me feel like this'."

Significantly, staff talk about how there was always someone else to hold some of the responsibility and they were never alone in caring for a family. Organisational structures appear to enable staff to feel supported in being boundaried and maintaining a good work-life balance.

"There's a real sort of safety there. Um, and that, that real kind of confidence that you… you can leave work and that your colleagues scoop up what needs to be done."

"So there's a real, real structure in place now that, kind of, ensures best practice for the families and also the wellbeing of the staff."

"That the Wellbeing Team hold some of it, and we hold some of it. I've never thought about it before, but thinking about it now, potentially yes, that helps us keep that separation as well."

"So, a lot of it probably helps actually, the shift patterns, the fact that you're not immersed in it the whole time."

Discussion

The findings of this study highlight the unique and complex experiences of using cold facilities to work with a family immediately following the death of an infant, adding to the scant evidence base in paediatric, and specifically neonatal, hospice care. With the increasing availability of small, portable options for maintaining an infant's deceased body either in hospice or through hospice care at home, findings are useful in understanding the experiences and needs of staff who are increasingly being asked to care for families in this way.

Given the literature on stress in hospice nursing and specific identified stressors within palliative care, one of the key assumptions the researcher took into this study was that there would be something intrinsically different about the experiences of caring for a deceased infant's body when thinking about other aspects of working in a paediatric children's hospice. As hospice work has been found to be stressful in terms of coping with constant exposure to death and dying (Lyall, Rogers & Vachon, 1976; Mount & Voyer, 1980; Melvin, 2012), it was assumed that this would be perceived as an additional stressor in some way. However, the presence of stress was not found to be a theme within results of this research. Though stress has been found to be lower in palliative care than other disciplines, particularly with nurses (Payne, 2001; Plante & Bouchard, 1996), it was surprising that no staff members reported feelings of stress in their work. Possible explanations for this are considered further on.

Though working alongside an infant's deceased body would perhaps seem challenging to those who do not routinely work alongside death, findings suggested that for this staff group it was not the aspects related to caring for the body which challenged them. These staff members were largely matter of fact about this part of the role, and acknowledged the deterioration of a body as a natural stage of the life cycle. Interestingly, in contrast to recent findings (McConnell & Porter, 2017), staff did not widely report challenges related to balancing their work within respite care alongside providing bereavement care after an infant's death. This may also be reflective of the sporadic nature of referrals through the neonatal pathway. Staff noted that they would not always have a family using the bereavement suite, and there could be a number of weeks between each referral; therefore it may be that this switching between respite and bereavement support is not perceived as a challenge due to the infrequency of this as part of their role. It is also possible that their years of experience have also moderated the challenges one might associate with managing conflicting demands within their roles (Feudtner et al., 2007;

Reid, 2013). It may be that the subtheme of 'experience' is not only reflecting how staff perceive their work within the neonatal pathway, but how they have made sense of their experiences within their wider job roles.

Some of the challenges staff identified in relation to the neonatal pathway were similar to those experienced by staff in both adult palliative care and paediatric palliative care. These commonalities included challenges in their relationships with families (Woolley et al., 1989; McCloskey & Taggart, 2010), circumstances of death (Vachon & Pakes, 1984; Woolley et al., 1989), and associations with self (Abendroth & Flannery, 2006). Challenges specific to the care of families after the death of an infant included staff's early experiences of caring for infants using cold facilities, which staff reflected were more difficult on both practical and emotional levels than their more recent experiences. It may be that hospice organisations need to pay particular care to staff beginning within this pathway in managing their wellbeing. In line with the wider literature on end-of-life care in children (Davies et al., 1996; Hackett & Palmer, 2010; McCloskey & Taggart, 2010; Papadatou et al., 1999; Pearson, 2013), staff found practices such as debriefing sessions particularly helpful in feeling safe to share experiences and emotions, and as opportunities to improve practice for future families.

Staff also found the short-term nature of the relationships developed with families after the loss of an infant a source of challenge; this was compared to the longer relationships often developed within paediatric hospice care. Staff reflected that this could sometimes make work within the neonatal pathway more challenging practically in terms of knowing how best to support a family, but could also find this easier on an emotional level by having less of an attachment to both the deceased infant and the family. Staff noted that they learned from each successive family that they supported in how to manage this different type of relationship building, and it appears that organisational structures

have allowed staff to share their experiences and expertise with each other to improve their practice.

Another aspect of this pathway that staff at times found challenging was related to the circumstance in which the infant had died. Although staff in paediatric hospices routinely deal with death and dying, staff reported finding it difficult to support a family when the deceased infant was a full-term infant. Staff shared that it was challenging when a deceased infant appeared healthy, as this could make them think of the loss of babies either in their own lives or the lives of their loved ones. They also shared that the loss of hope and potential could make the circumstances feel sadder to staff when supporting families through their loss. Staff found that an awareness of their emotions and appropriate use of peer and clinical supervision enabled them to cope with any difficult feelings they experienced.

Despite these challenges, results support findings in both hospice and at-home hospice care with children (Korzeniewska-Eksterowicz et al., 2010; McConnell & Porter, 2017), in terms of staff perceptions of work within the neonatal pathway being both positive and rewarding. Staff reflected that the ability to provide support that felt valuable for the families in a time of crisis helped sustain them long-term in their work. Staff were particularly positive about the impact that providing cold facilities had for parents in terms of moving through grief and accepting the loss of their infant in a protected and warm environment. It is worth noting that all staff interviewed were experienced members of staff who appeared both happy and fulfilled in their roles within the hospice, despite the challenges that could be faced within this pathway. Indeed, the accumulation of experience helped staff both in terms of their own self-awareness and also protecting them from experiencing the sadness and pain they are surrounded by. Connor (2009) noted that time

and experience in hospice care enables staff to learn to convey empathy and show caring without becoming so involved emotionally that they become ineffective or burnt out.

In line with previous studies (Barnes et al., 2001; McConnell & Porter, 2017), various self-care strategies were highlighted as important for staff in maintaining long careers in this field. These varied for each staff member, but there was an emphasis on the need for time to process their experiences and reflect on their emotional responses. Staff felt supported to do this through formal and informal support structures, as well as in their own time during work. Staff noted feeling under pressure when workload increased and they did not have this time to process, and it would be beneficial for organisations to schedule protected time for staff to process any difficult experiences where possible. Maintaining interests outside of work also appear to help staff to manage the balance between their professional and personal lives (Zimmerman, 1981; Barnes et al., 2001).

Staff highlighted other structures in place within their organisation which helped them feel supported and able to cope with the demands of their work. Staff particularly highlighted the effectiveness of informal support, both through peers and management, in making sense of any difficulties they experienced in the moment. This emphasises the importance of a workplace culture which enables staff to feel they can be open about their own emotional experiences when working in challenging environments, which in turn has implications on the quality of care that can be delivered (Maben et al., 2012). Staff also appreciated more formal structures, such as supervision (both internal and external) and debriefs after the death of an infant, which were in place as standard practice throughout the hospice organisation. These findings support previous research in terms of the hospice work environment being the gold standard in supporting staff through formal and informal support within the organisation (Woolley et al., 1989; McConnell & Porter, 2017).

It may be that there are personal characteristics or existential and spiritual beliefs enabling staff to work within such a specialist pathway, as has been noted in studies on stress in hospice care (Vachon, 1995). Specifically, it may be that the subtheme 'personal characteristics' in particular is a reflection of the traits and ways of making sense of challenges which make for a particularly resilient individual. A theory underpinning the understanding of resilience is the construct of hardiness (Kobasa, 1979). Hardiness is conceptualised as an aspect of personality which enables people to achieve a sense of satisfaction and growth from stressful circumstances (Maddi, 2002) and incorporates three primary dispositions; commitment, challenge and control (Kobasa, 1979). Commitment refers to an attitude of curiosity and interest in life, wherein you believe in the importance of involvement with others regardless of stressors. Control is about the extent to which you believe you can influence events from your efforts, and challenge refers to the belief that stresses are a normal part of life and can provide the opportunity for personal growth (Maddi, 2006). It is suggested that individuals high in these three attitudes are particularly hardy. The model of hardiness supposes that when both acute and chronic stressors are prolonged, health and performance can be negatively impacted upon depending on your overall vulnerabilities. However, hardy attitudes can result in patterns of behaviour which moderate stressors by routes such as building social support, developing appropriate problem-solving skills and practicing effective self-care (Maddi, 2006). It has been suggested that hardy individuals are particularly well suited to hospice care (Hutchings, 1997). Therefore it may be that this staff group's tendency to see challenges as opportunities to learn and develop their practice, as well as their commitment to the ideologies of hospice caring and belief in the value of their work, are reflective of hardy personalities. It could be that hardiness explains why this staff group do not report stressors inherent to their work, despite the literature suggesting hospice work can be stressful.

In addition to personal characteristics and length of experience, which may be helping staff defend from the more challenging aspects of their role in caring for families after the death of an infant, the positive relationships reported within the staff team may help to explain why staff did not report experiences of stress. As results have indicated that stress in paediatric palliative care is often linked to the work environment, and particularly conflicts within staff teams (Woolley et al., 1989, Alexander, 1992; Harding, 1996); it may be that staff are positive about their work as a result of having a stable staff team and good working relationships within the organisation.

Limitations

The findings come from a small children's hospice organisation, with a small sample size, and explore a unique pathway within this. Therefore the transferability to other hospices looking to provide similar services is limited. However, some of the findings overlap with a recent study of staff experiences in end-of-life paediatric hospice care (McConnell & Porter, 2017), suggesting experiences in using cold facilities with deceased infants and their families may be a similar experience to providing end-of-life care to children more generally. Further studies within paediatric hospices, and specifically hospices which offer this unique service, would be useful in triangulating the results.

While being open to a number of professional affiliations and with over 40 individuals attending recruitment presentations, only seven members of staff were available to be interviewed, and over half of this self-selected sample came from counsellors (n=4). Therefore the emphasis on reflection and self-awareness in the results from this small sample may have reflected the training and specific job role of a significant proportion of the sample. A more balanced sample would be advantageous in future research to ensure the experiences of staff such as healthcare assistants, art therapists and nurses were represented more fully. As staff in this hospice were facing a number of

changes in their work roles and environment, it may be that this sample is a particularly robust self-selecting group who were interested in taking part in research. As noted, staff may also be particularly hardy and further research could investigate this personality construct within paediatric hospice staff.

Conclusion

There has long been an understanding that the wellbeing of healthcare professionals influences the quality of patient care (Adams, Robert & Mayben, 2013; Boorman, 2009; Cornwell & Foote, 2010) particularly at end-of-life (Clarke & Quin, 2007; Korzeniewska-Eksterowicz et al., 2010; Morgan, 2009); therefore it is particularly useful to understand what mechanisms enable staff to work in emotionally demanding roles such as those in paediatric hospice care and in supporting families after the loss of an infant. Findings suggest that a culture where staff are supported in understanding and expressing their emotional reactions, and one which actively promotes the importance of formal and informal supervision and team debriefs may help to moderate the challenges in working alongside death (Lobb et al., 2010). It appears that for this group of staff, the unique challenges within using cold facilities with deceased infants are around their making sense of their first experiences, and challenges of supporting families they do not yet have relationships with. In organisations expanding to include this pathway, care should be paid to supporting staff early on in their roles of providing caring for families with an infant's deceased body present. The practices which enable staff to feel supported and enriched in their roles should include avenues for informal support, regular supervision, and reflective practices which enable learning and development such as debriefs. Ensuring that one staff member is not solely responsible for the care of a family helps ensure staff can maintain good work-life boundaries. Staff benefit from an experienced, stable team who are able to support and be supported by each other.

References

Abendroth, M. & Flannery, J. (2006). Predicting the risk of compassion fatigue: A study of hospice nurses. *Journal of Hospice & Palliative Nursing, 8(6),* 346-356.

ACT (2009). *A Neonatal Pathway for Babies With Palliative Care Needs*. Bristol, UK: ACT.

Adams, M., Robert, G., & Maben, J. (2013). 'Catching up': The significance of occupational communities for the delivery of high quality home care by community nurses. *Health (London), 17(4),* 422-438.

Alexander, D. (1992). Stress among palliative care matrons: A major problem for a minority group. *Palliative Medicine, 6,* 111-124.

Barnes, K. (2001). Staff stress in the children's hospice: Causes, effects and coping strategies. *International Journal of Palliative Nursing, 7(5),* 248-254.

Boorman, S. (2009). *NHS Health and Wellbeing Review*. London, UK: Department of Health.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3(2),* 77-101.

Braun, V. & Clarke, V. (2013). *Successful Qualitative Research*. London, UK: Sage.

Clarke, J. & Quin, S. (2007). Professional carers' experiences of providing a paediatric palliative care service in Ireland. *Qualitative Health Research, 17,* 1219-1231.

Connor, S.R. (2009). *Hospice and Palliative Care: The Essential Guide.* Oxford, UK: Taylor & Francis.

Cornwell, J. & Foote, C. (2010). *Improving Patients' Experiences. An Analysis of the Evidence to Inform Future Policy Development*. London, UK: The King's Fund.

Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J.,…
Stutzer, C. (1996). Caring for dying children: Nurse's experiences. *Pediatric
Nursing, 22(6),* 500-507.

Davies, R. (2005). Mothers' stories of loss: Their need to be with their dying child and
their child's body after death. *Journal of Child Healthcare, 9(4),* 288-300.

Denzin, N. K. & Lincoln, Y. S. (2011). *Handbook of Qualitative Research* (4th Edition).
London, UK: Sage.

Edi-Osagie, N.E., & Evans, V. (2005). Bereavement support in neonatal intensive care.
Infant, 1(6), 203-206.

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.

Feudtner, C., Santucci, G., Feinstein, J.A., Snyder, C.R., Rourke, M.T., & Kang, T.I.
(2007). Hopeful thinking and level of comfort regarding providing pediatric
palliative care: A survey of hospital nurses. *Pediatrics, 119(1),* 186-192.

Forrester, L. (2008). Bereaved parents' experiences of the use of 'cold bedrooms'
following the death of their child. *International Journal of Palliative Nursing,
14(12),* 578-585.

Gold, E.A. (1997). The role and need of the children's hospice in the United Kingdom.
International Journal of Palliative Nursing, 3(5), 281-286.

Hackett, A. & Palmer, S. (2010). An investigation into the perceived stressors for staff
working in the hospice service. *International Journal of Palliative Nursing, 16(6),*
290-296.

Harding, R. (1996). Children with cancer: Managing stress in staff. *Pediatric Nursing, 8(3),* 28-31.

Hutchings, D. (1997). The hardiness of hospice nurses. *The American Journal of Hospice & Palliative Care, 3,* 110-113.

Korzeniewska-Eksterowicz, A., Przysło, L., Grzelewski, T., Stolarska, M., Młynarski, W., Stelmach, I.,… Stelmach, W. (2010). Job satisfaction among health professionals of home hospice for children of Lodz region. *Advanced Palliative Medicine, 9(3), 67-72.*

Kaunonen, M., Tarkka, M.T., Hautamaki, K., & Paunonen, M. (2000). The staff's experience of the death of a child and of supporting the family. *International Nursing Review, 47,* 46-52.

Kobasa, S.C. (1979). Stressful live events, personality and health: An inquiry into hardiness. *Journal of Personality and Social Psychology, 37,* 1-11.

Lee, K.J. & Dupree, C.Y. (2008). Staff experiences with end-of-life care in the pediatric intensive care unit. *Journal of Palliative Medicine*, *11(7)*, 986-990.

Lobb, E. A., Oldham, L., Vojkovic, S., Kristjanson, L. J., Smith, J., Brown, J. M., & Dwyer, V. W. J. (2010). Frontline grief: The workplace support needs of community palliative care nurses after the death of a patient. *Journal of Hospice & Palliative Nursing, 12(4),* 225-233.

Lyall, W.A.L., Rogers, J., & Vachon, M.L.S. (1976). Report to Palliative Care Unit of Royal Victoria Hospital regarding professional stress in the care of the dying. In: *Palliative care service report, 457-468.* Montreal, Canada: Royal Victoria Hospital.

Maddi, S.R. (2002). The story of hardiness: Twenty years of theorizing research, and practice. *Consulting Psychology Journal, 54,* 173-185.

Maddi, S.R. (2006). Hardiness: The courage to grow from stresses. *The Journal of Positive Psychology, 1(3),* 160-168.

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

Manktelow ,B.N., Smith, L.K., Prunet, C., Smith, P.W., Boby ,T., Hyman-Taylor, P., … Draper, E.S. (2017). *MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2015.* Leicester, UK: University of Leicester.

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.

McConnell, T. & Porter, S. (2017). The experience of providing end-of-life care at a children's hospice: A qualitative study. *BMC Palliative Care, 16*, 15-20.

Melvin, C. S. (2012). Professional compassion fatigue: what is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing, 18(12),* 606-611.

Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing, 35(2),* 86-90.

Moro, T., Kavanaugh, K., Okuno-Jones, S., & Vankleef, J.A. (2006). Neonatal end-of-life care: A review of the research literature. *Journal of Perinatal & Neonatal Nursing, 20(3),* 262-273.

Mount, B.M. & Voyer, J. (1980). Staff stress in palliative/hospice care. In I. Ajemian & B.M. Mount (Eds). *The RVH Manual on palliative/hospice care.* New York, NY: Arno Press.

Office for National Statistics (2017). *Childhood Mortality in England and Wales: 2015.* London, UK: Office for National Statistics.

Papadatou, D., Papazoglou, I., Petraki, D., & Bellali, T. (1999). Mutual support among nurses who provide care to dying children. *Illness, Crisis & Loss, 7,* 37-48.

Payne, N. (2001). Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing, 33(3),* 396-405.

Payne, S.A., Dean, S.J., & Kalus, C. (1998). A comparative study of death anxiety in hospice and emergency nurses. *Journal of Advanced Nursing, 28(4),* 700-706.

Pearson, H.N. (2013). "You've only got one chance to get it right": Children's cancer nurses' experiences of providing palliative care in the acute hospital setting. *Issues in Comprehensive Pediatric Nursing, 36,* 188-211.

Peters, L., Cant, R., Sellick, K., O'Connor, M., Lee, S., Burney, S., & Karimi, L. (2012). Is work stress in palliative care nurses a cause for concern? A literature review. *International Journal of Palliative Nursing, 18(11),* 561-567.

Plante, A. & Bouchard, L. (1996). Occupational stress, burnout, and professional support in nurses working with dying patients. *Omega, 32(2),* 93-109.

Plante, J. & Cyr, C. (2011). Health care professionals' grief after the death of a child. *Pediatric Child Heath, 16(4),* 213-216.

Reid, F.C. (2013). Lived experiences of adult community nurses delivering palliative care to children and young people in rural areas. *International Journal of Palliative Nursing, 17,* 561-567.

Romesberg, T. (2004). Understanding grief: A component of neonatal palliative care. *Journal of Hospice and Palliative Nursing, 6(3),* 161-170.

Seale, C. (1999). *The Quality of Qualitative Research*. London, UK: Sage.

Tebes, J.K. (2005). Community science, philosophy of science, and the practice of research. *American Journal of Community Psychology, 35(3-4),* 213-230.

Vachon, M.L.S. (1995). Staff stress in hospice/palliative care: A review. *Palliative Medicine*, *9*, 91-122.

Vachon, M.L.S. (1997). Recent research into staff stress in palliative care. *European Journal of Palliative Care, 4(3),* 99–103.

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, NY: Hemisphere Publishing.

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.

Zimmerman, J.M. (1981). *Hospice – Complete Care for the Terminally Ill.* Baltimore, MD: Urban and Schwarbenberg.

Chapter 4.

Extended Methodology

Extended Methodology

Overview of Methodology

The research paradigm selected for the research is described, alongside the author's epistemological, ontological and methodological position (Guba, 1990). A justification for specific aspects of the research design is included, such as the use of semi-structured interviews. The author's own position is presented alongside the rationale for conducting a thematic analysis, to illustrate the appropriateness of thematic analysis in answering the research questions in line with the author's position. The study design, recruitment, sample and ethical issues are then described. The process of data collection and analysis are described in more detail, as the process of coding and analysing the dataset must be considered with particular reference to the quality and rigour of the data, and the trustworthiness, reliability and reflexivity of the author.

Rationale for Qualitative Framework

A qualitative framework allows for research to investigate the rich and complex insights, experiences and perspectives of participants with a depth that cannot be gathered through quantitative methods (Braun & Clarke, 2006), and is of particular use to healthcare research (Braun & Clarke, 2014). Qualitative methodologies are designed to generate thorough, contextualised data that furthers the grounded understanding of participants (Mason, 1996; Denzin & Lincoln, 2011). Approaching this research within a qualitative framework allows for a flexible and in-depth understanding of the experiences of staff who care for deceased babies and their recently bereaved families, through exploring a full account of what this work is like and how it is experienced on an individual level which would not be feasible through quantitative methods (Green & Thorogood, 2004, Braun & Clarke, 2013).

A qualitative approach was chosen due to the exploratory nature of the study and the need to better understand the depth of these staff members' individual experiences, as this has not been explored in the research base to date (Denzin & Lincoln, 2011). The use of 'cold' facilities in palliative care is not a widely explored area, with only two studies to date looking at the experiences of those who have experienced using them for the care of their loved ones (Davies, 2005; Forrester, 2008). Neither of these studies explore the use of cold facilities with infants, nor have any studies explored the experiences of the staff who care for others through using these types of facilities. Furthermore, advancements in technology have meant that the two existing studies are exploring somewhat different circumstances to those which hospices can offer currently (in terms of how the facilities are experienced by both service users and staff). Therefore a qualitative framework which allows for themes to emerge from these experiences could indicate the need for further quantitative follow-up research.

Rationale for semi-structured interviews

Semi-structured interviews were selected as they allow the research questions to be explored with a flexible structure which gives participants the opportunity to talk about their experiences in depth. Having a loose structure enables the interviews to follow unexpected routes of interest for participants, and individual meaning can be discovered through conversation (Denzin & Lincoln, 2011). By following a semi-structured approach to interviewing, themes may emerge which the researcher could not have foreseen, which is in line with the position of the researcher as inexpert in the area. In attempting to remove presumptions of what these staff experience in their work, a semi-structured interview allows for the participants to share what is meaningful and significant without being overly inhibited by pre-set questions. The researcher intended for the interviews to feel like a conversation between colleagues (Rubin & Rubin, 2012), free from judgement or critique.

This was felt to be important as the subject matter concerned content which many have strong emotional reactions to, and was exploring how staff felt able to do this work. With this comes a basic presumption that there is something difficult in the work they do, which is supported by the literature on nursing stress in palliative care. However, this layer of assumption had the potential to influence the way in which participants could respond. Therefore a loose structure without imposing a presumed emotional response was important in order to gain rich and authentic data from participants.

Rationale for Thematic Analysis

Thematic analysis aims to identify, categorise and report themes through a process of analysis and identification of the research data (Braun & Clarke, 2006). This has been operationalised to incorporate a six-phased approach to data analysis, allowing for meaningful patterns to be discovered through iterative coding processes (Grbich, 2013). This phased approach covers transcription, familiarisation with the data, coding, searching for themes within the codes, reviewing and defining themes and writing the final report (Braun & Clarke, 2013).

Thematic analysis was chosen for its fit with the epistemological stance of the researcher and its ability to answer the research questions, as well as its flexibility. It allows for staff experiences to be explored through the content of the interviews (i.e. bottom up) rather than using theoretical assumptions (i.e. top down). An inductive approach allows for connections to be made from the content of the data itself rather than from any theoretical stance or my expectations as a researcher (Braun & Clarke, 2006). Thematic analysis aims to identify themes across a group rather than each individual experience, which allows for insight into the experiences of a unique blend of professionals working through a specific care pathway in palliative care. Thematic analysis most

appropriately answers the research questions as it enables exploration of what this area of hospice care is like for the staff who work within it.

A Priori Decisions about the Analysis

Braun and Clarke (2006) suggest that before beginning analysis, decisions need to be made regarding how themes will be sorted and the level of interpretation being undertaken. These decisions were made with the support of the supervisory team prior to data collection beginning. As the research represented an area of work which had not been specifically investigated before, it was decided that the thematic analysis should be inductive with themes generated directly from the data, as described above.

It was decided within the research team that data would be analysed semantically as opposed to on a latent level, as this enables the focus to be on the words said by the participants rather than an interpretation as to their possible meaning. This was decided due to the paucity of research in the area, and respect to the participants as experts in the areas of discussion and the researcher as curiously inexpert. Finally, it was decided that only themes which related to the research questions would be included in the analysis. Additional commonalities within the data corpus (Braun & Clarke, 2006) will be reported in the critical analysis for completeness and to highlight potential areas for further research.

Ontological and Epistemological Position of the Research

In order to maintain the integrity of the research process, it is important to clarify the epistemological and ontological frameworks being adopted in the research (Mason, 1996), as these positions and assumptions directly influenced the decision making process for both methodology and analysis. Transparency over these positions and decisions is

vital for understanding the underlying assumptions that the researcher has taken into the research process, which enables the validity and rigour of the research to be assessed.

Ontology

Ontology refers to the study of the nature of reality (Morrow, 2007), and concerns whether there is an objective reality (positivism) or whether reality is a subjective construct within the mind (interpretivism) (O'Gorman & Macintosh, 2015). An objective, positivist view of reality is reflected in quantitative methodologies in research; that is, a measurable, objective truth is being sought. An example of this objective understanding of reality could be seen as measuring the size of people's feet; this could be measured and quantified easily. However, a qualitative, interpretivist account might be more interested in the felt experience of what it is like to have a certain foot size in comparison to others. The ontology of this research was clearly interpretivist, as it focused on staff's descriptions of what it is like to carry out the work they do. The shared understanding and meaning making being co-constructed between researcher and participant (Guba & Lincoln, 1994) was central to the study, and was not about finding an objective truth or reality but in understanding the significance of the felt experiences of an objective experience (e.g. doing physical checks on a dead body). As well as the subjective experiences of the participants, the research reflects the way in which the researcher has approached the study, with subjective viewpoints and assumptions which may influence the project and the ways in which data is gathered (Morrow, 2007). A reflective diary was kept throughout the data collection process to explore this possibility.

Epistemology

Epistemology refers to the philosophical study of how knowledge is acquired and the relationship between what is known and the knower (Sleeter, 2001). It attempts to answer the question of how we can come to knowledge, and differentiate between what is true and

false. Within this study of knowledge, the three main positions are positive, critical realist and interpretivist (Mikkelsen, 2005). The epistemological framework of this thematic analysis will be interpretivist in its rejection of the view that knowledge exists in the world independent of consciousness (Collins, 2010). In taking an interpretivist stance, this research accepts that reality is subjective and multiple (Lincoln & Guba, 1995) and are dependent on other systems in place (Neuman, 2000). Under this broad interpretivist epistemology, this research takes on a social constructionist stance with an emphasis on contextualism. It is underpinned by a belief that the way sense is made of the world is through the social processes one is a part of and is therefore culturally and historically dependent (Tebes, 2005; Braun & Clarke, 2013). A contextualist perspective further supposes that there is a relationship between a person's account of their experiences and the situations in which these occurred (Madill, Jordan & Shirley, 2000). This allows for consideration of the layers in which a person experiences their world and what their experiences are influenced by, and additionally the context the researcher brings. Through a constructive and contextualist stance, no objective truth is being sought but rather the data reflects the "interaction between the data and the interpretive framework that the researcher brought upon the data" (p.35, Lyons & Coyle, 2007). The context of the participant will therefore contribute to the narratives produced (McGuire, 1983) and the findings will be specific to the context of hospice work and the context of the interview process itself (Fontana & Frey, 2011).

Personal statement: Own Position (First Person)

I am a 32-year-old woman in my third year of training to become a Clinical Psychologist. I am employed by Cambridge & Peterborough NHS Foundation Trust, and have primarily worked in clinical placements within Norfolk & Suffolk NHS Foundation Trust during my training. I have a BA in Combined Social Sciences (accredited by the

British Psychological Society as providing Graduate Basis for Registration), and an MSc in Developmental Psychopathology. I have published elements of my undergraduate dissertation which employed a quantitative methodology and a cross-sectional design looking at adult attachment anxiety and relationship threat, as well as published a review paper on self-rating assessment measures for identification of those at risk of developing bipolar spectrum disorders from my work as a Senior Research Assistant. This study represents the first time I have used a qualitative methodology in my research career, though I have received training in qualitative research methods in my undergraduate, masters and doctorate programmes.

As a Trainee Clinical Psychologist, I have always felt inclined towards working within particularly marginalised groups and over the past three years my clinical interests have moved towards working with people who have significantly different professional and personal experiences to my own. Clinically this has led me towards working within forensic services, and has enabled me to have conversations about some of the 'darker' areas of the human experience. It has surprised me that my curiosity and empathy have extended to being able to talk about and work alongside quite harrowing experiences, within the lived experiences of both victims and perpetrators. I have realised through my journey of clinical training how powerful and freeing it is to be able to talk about death and dying in frank, honest terms and this has become a regular feature of my work. As this has developed in the past few years, it has surprised me to find that I have not felt emotionally challenged by many of these conversations. To me, working through death and grief felt like a normal part of the human experience and I have found it fairly straight forward to talk about death without becoming immersed in the subject emotionally. It is when sharing small aspects of my working life with others both within caring professions and outside, that I see what strong negative reactions people widely have to talking about death. This led me in a very linear way towards exploring what it is to work in hospice care, and

particularly this area where death is being confronted in quite a concrete and physical way. In this hospice, all staff members will have gone into their work knowing that their patients have life-limiting conditions and may die in the future, but there is this additional pathway of their work where staff are in the room with a deceased body and caring for both the immediately bereaved and also the physical body of the deceased loved one. To me, I have the same reaction to this part of the staff's work which others seem to have when talking to me about my clinical work; which is to say, 'oh wow, I can't imagine doing that every day'. There is something about it which makes me, a person comfortable speaking about death, assume that it must be incredibly challenging.

I accept that I take this assumption into the research process with me; I accept that without this perspective, the impetus to conduct the research would be removed. It is an essential part of developing the research questions; for something to be of academic interest in this area of work, there must be something worth exploring and understanding that is different to the norm or expectation. Yet this assumption of difference and challenge means that I cannot come into the research process with neutrality. This fits within the interpretivist epistemological position, however; and accepts that the relationship developed between participant and researcher will build a co-constructed understanding of their experiences and the context of the research and interview process is taken into consideration.

Procedure

Ethical Review & Approvals. The proposal for this project was submitted for review by staff within the Clinical Psychology Department at UEA and was approved (Appendix D: Feedback on Thesis Proposal). Feedback related to the methodology was attended to prior to submitting the project for ethical review with the Faculty of Medicine & Health Sciences (FMH) Research Ethics Committee. Small amendments were

recommended from the initial submission, and changes were made in line with this prior to

ethical approval being granted on 10th March 2016 (Appendix E: Approval from FMH

Research Ethics Committee). As the research was being conducted within a private charity,

local approval was sought from the organisation's Clinical Governance Committee prior to

approval from FMH Research Ethics Committee. Approval of the Board was granted on

10th May 2016 further to FMH Research Ethics Committee's final approval (Appendix F:

Approval Letter from Hospice Clinical Governance Committee). Prior to recruitment

beginning, amendments were needed to the participant information sheet due to a minor

change in the wording about the care pathway. Approval for this amendment was granted

by the FMH Research Ethics Committee on 29th April 2016 (Appendix G: Amendment

Approval from FMH Research Ethics Committee). Recruitment began in May 2016 and

the first participant consented on 20th May 2016.

Recruitment Procedures. Braun & Clarke (2013) have made recommendations for

sample size when conducting a thematic analysis, depending on the size of the project

being conducted. For a medium sized project (e.g. UK professional doctorates), a sample

of 10-20 was deemed sufficient to conduct a thorough thematic analysis. However, it has

been noted that it was unclear where the suggested numbers were derived from aside from

a justification that these numbers would allow for patterns to be found without having an

unmanageable amount of data (Fugard & Potts, 2015). There has been wide debate on the

topic of sample sizes, and other researchers have suggested that an appropriate sample size

could be as small as six to 10 interviews, as saturation of themes has been found to occur

beyond this point (e.g. Guest, Bunce & Johnson, 2006; Francis et al., 2010; Isman, Ekéus

& Berggren, 2013). Additionally, other factors such as time, resources and the research

questions should be considered in decisions on sample size (Baker & Edwards, 2012). To

this end, it was agreed within the supervisory team that an objective of recruiting 10

participants would be appropriate for answering the research questions with the resources

available. Out of approximately 40 members of eligible staff who the study was presented

to, a total of 12 staff members expressed interest in taking part in the research, and seven

interviews were eventually conducted. Recruitment was complicated by delays to doctorate

training for the primary researcher, alongside significant organisational changes within the

hospice during this time. The additional five potential participants either failed to respond

to communication inviting them to interview, or interviews could not be scheduled in the

time available within the research process. The research process had already been extended

in order to continue recruitment; however, it was felt that we had recruited all the

participants currently interested in and able to take part in the study. Therefore, a decision

was made with the primary supervisor to end recruitment and complete the thesis within

the planned timeframe. After reading a subsection of the interview transcripts, it was

agreed with the Primary Supervisor that the richness of the data was sufficient to answer

the research questions.

Inclusion and Exclusion Criteria. The inclusion criteria were that participants

should be staff members who identify themselves as providing a significant supportive role

in working with families after the loss of an infant, who are involved in supporting families

after the loss of an infant for the duration of their stay at the hospice and who have been in

their job roles for at least one year. Participants also had to have supported at least two

families through the use of a FlexMort CuddleCot™, to ensure that they were experienced

within this part of the care pathway. There were no exclusion criteria for this study.

Recruitment Strategy. A purposive sampling technique was utilised to ensure that

participants were sufficiently experienced in their work, to ensure the data would be

'information rich' (Patton, 2002; p.230). It was hoped that the sample would be stratified

within the population to capture the breadth of experience in supporting families (e.g.

different types of professionals within the team). While this breadth was achieved, this was

by way of a convenience sample (Braun & Clarke, 2013) due to difficulties in achieving recruitment goals. Possible explanations for recruitment difficulties will be explored further on.

Staff were recruited through two routes. The first recruitment strategy involved the author presenting the study at regular staff meetings at the different hospice sites. The background to and rationale for the study were explained to relevant teams within the organisation, and there were opportunities for staff to ask questions and discuss the project with the author. All present staff members were given copies of the Participant Information Sheet (Appendix H), Consent Form (Appendix I) for consideration and an Expression of Interest form (Appendix J) along with pre-paid return addressed envelopes. Staff were invited to return the Expression of Interest form if they were interested in discussing their involvement in the study. This ensured that staff had time to consider the Information Sheet and Consent Form in their own time, and make an informed decision about their involvement.

The second route for recruitment involved managerial contacts within the hospices identifying other appropriate members of staff who would not have had the opportunity to attend the team meetings through purposive sampling. A non-supervising manager then forwarded an email from the author attaching the Participant Information Sheet and instructions on how to contact the researcher for more information. In order to avoid staff feeling coerced to take part in the study in appreciation of the power dynamics of having a manager send the email, careful wording of the email was agreed with two senior members of staff to ensure there was no pressure coming from management for staff to be involved.

Recruitment began on 10th May 2016 when approval was granted from the hospice Clinical Governance Committee and ended on 2nd July 2017. Seven participants were recruited and all data was used in the analysis.

Informed Consent. Informed consent was obtained from all participants included in the study. Each participant had received the Participant Information Sheet at least one week prior to being interviewed, which outlined the scope of the study and what would be expected of them. This was done to ensure participation did not feel coerced or pressurised into taking part, and further understood the implications of being involved in the study.

Participants were informed that their involvement was entirely voluntary and could be withdrawn at any stage, without any reason being needed, prior to the data being extracted and analysed. Contact details of the researcher and research team were included on the Participant Information Sheet and the withdrawal procedure was reiterated prior to and immediately following the interview.

Data Protection & Anonymity. Participants' anonymity was ensured by assigning each participant with a unique code, which they are referred to throughout the study. The participants' identifying information and corresponding code were kept on a password protected Word Document file, which was stored on an encrypted USB device. Although participants were asked to think about their experiences supporting families, they were explicitly reminded about confidentiality and asked to be mindful of disclosing any potentially identifying information that might jeopardise their anonymity. If any information was inadvertently disclosed, a discussion was had during and after the interview to agree on which parts of the interview would be omitted or anonymised.

A discussion was also had with each participant prior to interview about the importance of maintaining their anonymity within a small staff team, particularly as quotes would be selected from the interview for inclusion in the final papers prepared for thesis submission and publication. Staff were given the opportunity to validate both the interviews and subsequent themes on the Consent Form, and informed that at this stage they could request any passages to be omitted from direct quotes. Staff who opted to

validate their transcript were given a Confirmation of Accuracy Form (Appendix K) and self-addressed and postage paid envelope to send to the researcher.

Interviews were recorded on a Dictaphone and transferred to an encrypted memory stick at the conclusion of each interview. The recordings were then deleted from the Dictaphone in front of each participant. The eventual transcripts were also stored on an encrypted memory stick.

No deception was used in this study and all aspects of the research procedure and aims were explicitly outlined in the Participant Information Sheet. As staff were being asked to talk about routine aspects of their working life, it was considered unlikely that this would cause distress to participants. However, participants were encouraged to seek support either within the hospice or the supervisory team if they became distressed by the interview. Additionally, as participants were being asked about their feelings about the work they do and the organisation, support was offered from the Primary Supervisor if any issues arose relating to their work that they felt unable to speak about internally.

Interview Procedure. Participants agreed a mutually convenient time to meet the researcher, and interviews were conducted on site at the hospice within the participant's normal working hours. It had been agreed with management that interviews would be taken from time on their ordinary shifts, to ensure that staff members were not in any way penalised for taking part in the research. Interviews were held in a conference room separate to the suite of rooms for use with bereaved families. This was decided to ensure service user confidentiality and also to give participants a space separate from their work to think about their experiences. The Consent Sheet was signed at the beginning of each interview, and demographic information was collected (Appendix L: Demographic Information Sheet). The overall objectives of the research were reiterated to each

participant prior to the interview beginning, to ensure participants understood the context of the information being elicited.

Interviews were conducted solely by the researcher and lasted between 55 and 65 minutes. The average length of interview was 62 minutes. After interview, the recordings were transferred to an encrypted USB stick by use of the researcher's personal laptop. Consent forms were transported in a locked briefcase to University of East Anglia, where they were scanned, password protected and transferred to an encrypted USB memory stick. Hard copy consent forms were retained by the Primary Supervisor at the University of East Anglia in a locked filing cupboard.

Demographic Information. Demographic information was gathered on a Demographic Information Sheet (Appendix L) in order to understand the characteristics of the sample, and these variables included: age, gender, ethnicity, length of time in current post, length of time working in a caring profession, qualifications and any additional professional development training. These variables are reported in Table 1.

Semi-structured Interview. A preliminary topic guide (Appendix M: Preliminary Topic Guide) with a selection of possible questions to answer the overall research questions was devised with the Primary Supervisor and refined through consultation with senior members of staff at the hospice organisation and the Stillbirth & Neonatal Death Society (SANDS). Through final consultation at the hospice, an interview schedule (Appendix N) was created to attempt to answer the research questions whilst being sensitive of the risk of priming participants to respond in a directed emotional way. The schedule was used in a flexible way in order to allow the participants to explore areas of their experiences that were significant to them (Braun & Clarke, 2014). It was important that the questions focus staff on their role within this particular part of the care pathway, and their internal experiences of providing this type of care and support to families.

Questions focused on parts of the work that may have made an impact on the participant, without presuming that any aspect of this care pathway was negative, particularly emotionally demanding or challenging. As this study aimed to understand the experiences of these staff members, specifically asking for accounts of difficulties or coping may have elicited socially desirable responses designed to please the researcher rather than reflecting their experiences (Braun & Clarke, 2013, Patton, 2002).

Table 1:

Demographic information of participants

Participant	Age	Gender	Ethnicity	Length of time in post	Length of time in caring profession	Qualifications	Additional professional development training
P01	35	F	White-British	8 years	13 years	Undergraduate Psychology Degree, Diploma in hospital play specialism	Systemic Family Therapy (5 days), studying for integrative counselling diploma (through organisation.)
P02	42	F	White-British	19 years	24 years	Diploma in Counselling	N/A
P03	34	F	White-British	5 years	7 years	Undergraduate Psychology Degree	Systemic counselling training (6 weeks)
P04	30	F	White-British	8 years	8.5 years	Undergraduate Nursing Degree (Paediatric)	Undertaken module in End of Life Care
P05	46	M	White-British	5.5 years	26 years	Undergraduate Social Work Degree	Studying for integrative counselling diploma (through organisation)
P06	59	F	White-British	6 months (new post) – 25 years within organisation	25 years	Undergraduate Nursing Degree	Play Specialist, systemic counselling training (6 weeks)
P07	39	F	White-British	10 years	20 years	Undergraduate Nursing Degree	N/A

The interview schedule included prompts for if participants answered in ways which were largely task focused, as well as follow-up questions for identifying what it was about the experiences that had impacted on staff members. This was reviewed with the Primary Supervisor after the first interview and wording was amended slightly to elicit more specific instances of when an experience has stayed with a participant.

Transcript Validation by Participants. Interest in validating the accuracy of the transcript was gathered through the Consent Form, wherein participants could tick if they would like a copy of the transcript to confirm the accuracy of the account. Four participants answered yes, and they were provided with a Confirmation of Accuracy Sheet (Appendix K) and a return addressed postage-paid envelope to return after they had been emailed their transcript. Emails were password protected, and two participants confirmed via email that this was an accurate reflection of their interview. The remaining two participants were sent a reminder email about validating their transcripts, but no reply was given.

Researcher Experience of Conducting Interviews (First Person). Each of the interviews felt relaxed with rapport being developed quickly with each participant. I wondered if this was about the fact we were both professionals used to having difficult conversations with relative strangers and both presenting as 'at ease' and trying to make the other person in the room feel comfortable. It was clear from the interviews that the hospice placed a value on reflective, open communication in their staff; everyone appeared comfortable with discussing both the practical and emotional experiences of engaging in their work. At first, I felt unsure of how to approach the wordings around death and bereavement, but it was clear that each person was used to talking about end-of-life in warm but clear ways. For each participant, the interview started on a task-focused topic to

attempt to ease the interview into more personal and emotive experiences; I wanted participants to speak about what a typical day was like working within this pathway. It was clear that some participants were more attuned to their own emotional responses than others, and at times it was difficult to elicit the personal meaning of experiences for some participants. Some participants were able to tap into experiences which touched and stayed with them more readily than others, but all appeared open and unguarded in their responses to me.

Most participants were keen that the interviews were useful for me, and said things like 'I hope I've given you enough to work with' and 'I don't know if I've answered how you were hoping'. I got the sense that participants cared passionately about the work they did and were keen for research to be conducted that reflected this; it did make me wonder about whether this interest was inhibiting any more negative expressions of the work at times, though I did not get the feeling that any participants were being particularly cautious in how they spoke to me. A number also talked about how nice it was to be able to sit and think about the work they do, and reflect on their experiences with someone external to the organisation. It felt like the interviews provided almost a therapeutic space to consolidate for some participants, which I was mindful of in terms of how I responded to each participant. This feeling of a therapeutic space was one which felt useful in eliciting honest and thoughtful responses from participants, though it made me mindful of trying not to step into a clinical role in how I responded.

Thematic Analysis

All stages of the thematic analysis were carried out by the researcher, and are reported below.

Transcription. Each interview was listened to initially before transcription, and the researcher made notes about thoughts and feelings, as well as loose patterns to the data, in

a reflective diary. The researcher transcribed each interview, and listened to each interview again alongside the transcript to ensure they were accurate. Changes were made until the researcher was certain that the transcripts were a true reflection of each interview, and all potentially identifying information had been removed or adjusted. Each interview was transcribed within 24 hours of the interview taking place, to ensure that the material remained fresh in the researcher's mind. The reflective diary was updated with each transcription to capture further thoughts and feelings for this stage of the process. As Braun & Clarke (2006) advised, the entire data set was read before and after coding.

Coding and Searching for Themes. In line with taking an inductive approach to thematic analysis, codes were generated from the data for their relevance to the research questions. This is reflected in the different number of codes generated per participant, and codes were kept close to the original wording of the participants (Appendix O: Example Transcript and Codes). It was decided within the research team that material within the data set that did not answer the research questions would be considered in the wider critical analysis, however, particularly in terms of potential directions for further research. It was acknowledged that the research questions came from an inexpert position with a number of basic assumptions in place, and as such it was important to not discard any of the significant experiences brought up by participants.

Coding was done by hand, through a process of systematically identifying interesting elements of each data item and organising them into repeating patterns (Braun & Clarke, 2006). Codes were identified and matched to specific instances within the data corpus and sorted into possible themes (Appendix P: Example of initial coding groups). At this stage, the researcher searched amongst the code for repetitions or similar codes and regrouped or deleted these as appropriate. For example, an initial theme was created from grouping together the following codes; when participants spoke of challenges associated

with caring for families where they thought of their own families (three sources, five references), related experiences to their own situations (four sources, six references), or compared deceased children to their own at particular ages (four sources, eight references). These codes were grouped under the theme 'Associations to Self' initially, which later became a subtheme, and this process was continually repeated with each code. Multiple sections of interview transcripts were blind coded by the researcher and the primary supervisor and compared against each other, in order to confirm the validity of the codes and insure that relevant data within the transcripts was not being missed.

It was important to consider each code in terms of the overall research questions, and consider whether what was being said was a description of the work or a consideration of what it was like to do the work. When looking at codes, it was important to consider whether a piece of data was explanation of making sense of an experience, or an example of the participant making sense of the experience in the interview.

Reviewing and Renaming Themes. The researcher sent the primary supervisor regular emails about themes, and these were reviewed electronically and in supervision throughout the research process. In supervision, this involved reviewing the map of themes and subthemes against groupings of codes and debating whether or not the subtheme had enough prominence within the data corpus. The internal homogeneity of the themes was checked by repeated reading of codes and quotes, which resulted in some themes being merged and some being discarded. This was done to ensure that the data within themes fit together, and was done in collaboration with the primary supervisor. The external homogeneity of the themes was checked by reading themes together to ensure they reflected the overall sense of the dataset, while being distinct from each other (Patton, 1990). The titles of themes and subthemes were repeatedly reviewed and changed in collaboration with the primary supervisor to ensure that the analysis was an accurate

reflection of the data corpus. An example of this can be seen in how an overall theme was originally labelled 'What makes the work challenging'; it became clear from reviewing the reflective journal and in supervision that this was a value judgement coming from an assumption the researcher had about the work, and did not describe what the participants were saying. Through reviewing the subthemes, quotes and reflections it became clear that participants were talking about individual challenges rather than finding the work challenging, and thus that the theme was changed to 'challenges within the pathway' (Appendix Q: Reflections on Theme Review).

Thematic maps were created for each of the themes, and reshaped through review with the primary supervisor. This was done through a process of reviewing quotes attached to each initial code, separated by subtheme, to ensure that each subtheme told a contextual story about either what was a challenge or what enabled staff to overcome each challenge.

Analysis Credibility. Throughout the research process, the credibility of the research was checked using the following methods:

1. The first author attended the Qualitative Research Forums at University of East Anglia, held for Trainee Clinical Psychologists in order to discuss and review qualitative ideas and research processes.

2. The first author sent transcripts to the primary and secondary supervisors in the early stages of data collection to check on the appropriateness of the interview questions in answering the overall research aims, as well as reflecting on the techniques used by the researcher in conducting the interviews.

3. A coding session was attended by the primary supervisor, where sections of transcript were blind coded and then compared against codes already identified by the researcher. This process was also carried out with two external Clinical

Psychologists adept at qualitative research who were sent different sections of transcript to blind code.

4. Supervision with the primary supervisor was held monthly throughout the research process. Frequency was increased during the data collection phase of research as well as in the analysis.

5. Supervision was used with the secondary supervisor in the early and middle stages of data collection for shaping the thematic analysis.

6. Themes were reviewed and reconstructed throughout the analysis through discussion with the primary supervisor via email and supervision. External validation was sought from the primary supervisor in checking assumptions about what linked the themes and subthemes before final review and agreement of the data.

Rigour. In qualitative research, rigour is ensured through systematic and conscientious attention paid to the processes from the beginning of the design through to the communication of the findings (Mays & Pope, 1995). Trustworthiness is achieved through transparent methodology, analysis and reflections to ensure that the research provides a credible and clear explanation for the phenomenon being explored. Often rigour is related back to terms used in ensuring the trustworthiness of quantitative methodologies, and Guba and Lincoln (1989) set out criteria for assessing this in qualitative studies. They state that establishing trustworthiness relied on a study meeting criteria for credibility, transferability, dependability and confirmability.

For research to be credible, researchers attempt to show that an accurate depiction of the phenomenon is presented. For research to be transferable, enough context must be given to ensure the reader can know if findings are generalisable to other settings. In terms

of dependability, the research must aim to provide enough information for the study to be replicated. This is particularly important in terms of transparency over the analytical process. Finally, for research to be confirmable the research must be transparent about the degree of neutrality taken to ensure the findings have been shaped by the participants' experiences rather than the researcher's bias.

Specific, comprehensive guidelines for how to meet the above criteria are set out by Elliot, Fischer and Rennie (1999). These guidelines stress the importance of owning one's perspective, which has been outlined in the personal statement as well as the epistemological and ontological perspectives above. This allows readers to interpret the researcher's understanding of the data and their understandings (Braun & Clarke, 2013). The importance is grounding the research in examples from the data is stressed, to demonstrate the fit between the data and the researcher's interpretation of them. Credibility checks are recommended and to this end, the present research aimed to meet this through member checking (Seale, 1999), wherein participants review their interview transcripts and initial analyses to confirm that what was transcribed was what the participant intended to communicate (Guba & Lincoln, 1989). The guidelines also highlight the importance of the research being coherent and communicated in a way that resonates with the readers. As these criteria cannot be assessed objectively by the author they have been omitted from the methodology.

The remaining guidelines (situating the sample and accomplishing general vs. specific research tasks) are discussed and applied to the research below.

Situating the sample. Situating the sample is necessary to help the reader establish the ways in which the findings might be related to other settings. By detailing the context of the setting and participants, readers can decide how these findings could be translated to other areas.

All participants included in this research were staff members of the hospices, coming from a mixture of professional affiliations including nursing, counselling and managing. They worked within the Wellbeing Teams and Care Teams, which had different functions within the neonatal pathway in the hospice. Prior to the research beginning, there had been a number of changes within the organisation to the way in which care was delivered. This resulted in established staff members being repositioned within the organisation, and expectations changing within both teams to ensure that each aspect of care could be delivered by anyone within the teams (universal system). This meant that staff were experiencing a period of change with increased pressures in their daily work, which the managerial team made the researcher aware of.

It is important to acknowledge that these pressures being faced may have impacted on which members of staff felt interested in and able to take part in the research. It may be that the participants who felt able to talk about their work were a self-selecting sample of very experienced staff who felt the most positive about their work and the best supported, and able to manage a stressful transition time alongside taking part in research. Therefore it is important to keep this consideration in mind when looking at the results from this group of staff; they may not be representative of the wider staff team in this hospice. Additionally, the research explores one facet of the staff's work within the hospice, rather than the overall experience of working in palliative care. This means that consideration needs to be paid to the context of the staff members within the hospice, and the angle from which the research questions are explored. The research questions presumed there were inherent challenging demands involved in this type of work, and by interviewing staff with long careers within the organisation, the analysis may not reflect the experiences of other hospice staff.

Accomplishing general vs. specific research tasks. This research has focused on accomplishing specific research tasks, in that it sets out to understand the experiences of a small subset of staff members through studying and describing their experiences systematically and comprehensively (Braun & Clarke, 2013). The sample and sample size have been selected based on accepted qualitative guidelines detailed above, and the specificity of the research task was established in making a priori decisions regarding the analysis.

Chapter 5.

Critical Analysis

Critical Analysis

Discussion of results

In view of the evidence base relating to stress in caring for those in palliative services, both in adult and paediatric settings, it was surprising that stressors were not widely noted within the data corpus. The questions were kept open enough to not suppose the emotional experiences staff might have with doing this part of their work, but questions were designed to elicit any emotion staff might have in thinking about the neonatal care pathway. Especially when considering the context of change the hospice had recently undertaken, it was surprising that more challenges or stressors were not identified. This could be for a number of reasons, both theoretically and practically.

From a practical perspective, it may be that the self-selecting sample interviewed were a subset of staff who were both particularly robust and who felt positive about their work amidst a period of change and increased workload. At the beginning of the research process in 2015, managerial staff within the primary hospice had felt that it would be easy to recruit at least 10 participants from one hospice, and the research procedures would need to highlight how to deal with an overflow of interest from staff. By the time recruitment concluded in September 2017, only seven members of staff were recruited across two sites. This may reflect an overly ambitious view of the research process by management initially, but it could also be highlighting how the wider staff team was dealing with the changes within their organisation. There had been a number of changes not only to the ways in which care was delivered in the neonatal pathway and across the hospice, but also in specific staff members' roles. The participants in this research had all been employed for a number of years, and the sense from the interviews was that they were positive about the hospice organisation and their roles within it. Results may have looked different had a

different set of staff been interviewed; particularly any who had been at the hospice a shorter length of time, or who had been struggling with any of the recent changes.

In repeatedly re-reading the transcripts, there was an underlying sense that while staff were attuned to the emotional context of their work, and conveyed emotional and touching stories within their experiences, they did not appear to struggle with managing their own emotions, and did not seem to struggle with any stressors. As noted in the results of Chapter 3, it may be that these seven staff members represent particularly hardy personality types with an efficient way of dealing with workplace demands. This theoretical construct was considered through the process of conducting and reflecting on the interview process, and attempting to make sense of the various elements of what the researcher felt was unsaid. Wider research into hardiness in healthcare, and specifically in acute nursing, indicates a relationship between the construct of personality hardiness, stress and job satisfaction (Abdollah, Abu Talib, Yaacob & Ismail, 2014; Judkins, 2004; van Servellen, Topf, & Leake, 1994; Wright, Blance, Ralph, & Luterman, 1993). A high level of hardiness was also linked to high levels of job satisfaction and low levels of stress in at-home hospice nurses, particularly in the domains of commitment and control (Judkins & Rind, 2005). This suggests that hospice nurses who do not give up under pressure and who feel influential in the work they do experience more satisfaction within their work and experience less stress.

In relation to the results of this study, the subtheme of 'personality characteristics' emphasises the multiple references in the data corpus where staff talk about learning from their challenging experiences and difficulties enabling them to improve their practice (both individually and within their wider teams). This may be reflective of individuals high in the hardy attitude of 'challenge'; this tendency for the participants to see challenges as opportunities to grow may also be affecting whether or not a situation is perceived as being

stressful. The demand-control-support model of occupational stress (Johnson & Hall, 1998) suggests that the perception of strain at work comes from a combination of high demands, a perceived inability to meet those demands and a lack of support from managers and peers. This fits with the model of workplace stress developed by Vachon (1987) specifically in relation to end-of-life care. This model views workplace stress as the result of the fit between a person and the environment they are in, and posits that stress is experienced when a person's perceived demands exceed their perceived abilities to cope with these. Vachon identified that personal variables which influence a person's perception of stress include demographic variables, social support, personality, and the present or previous experience of other stressful life events. Work stressors can include the work environment, job role, illnesses at work and also patient care. It is identified that as stress results from factors both personal and within the workplace, coping mechanisms should be both organisational and personal. It may be that staff in the present study did not report experiences of stress because of a sense that their demands at work do not exceed their ability to cope with them, and their perceived support enables them to manage the demands inherent in the work.

It is also possible that despite the open and supportive structures that staff members talked about, it may be that staff still could have felt unable to talk about certain aspects of their emotional experiences regarding the deaths experienced within the neonatal care pathway. Research has noted that can be a cumulative grief response in staff who work within palliative care (Owen, 2000; Wakefield, 2000), and nurses dealing with dying patients have been described as 'disenfranchised grievers' (Kaplan, 2000). This is a term given to grief which is not socially acknowledged (Doka, 1989), and it has been noted that healthcare professionals often feel unable to openly acknowledge their own grief related to patients (Lee & Dupree, 2008). In a study investigating different types of healthcare professionals' experiences of grief responses, Plante and Cyr (2011) found that all

participants described 'suffering from the emotional, social and spiritual impact of bereavement' (p. 215). However, they also found that healthcare professionals who were older and more comfortable in caring for dying patients expressed fewer grief responses than other healthcare professionals. It could be either that staff in the present study felt unable to openly discuss grief responses as noted in other research, or their years of experience and feeling confident and comfortable in providing palliative care could be minimising the intensity of any grief responses they have.

Strengths and Limitations of the Thesis Portfolio

This study represents an important addition to the small evidence base looking at the use of 'cold' facilities, and is the first study conducted to consider staff experiences of using these facilities within their wider roles in children's palliative care. By interviewing participants experienced in this particular care pathway, rich data were gathered regarding their experiences and the sense that is made of them.

As noted, the particular sample reflects both strengths and weaknesses to the research. While results do indicate what works well within the children's hospice setting, and emphasises structures and practices in place which seem to enhance staff's abilities to cope with the demands, it must be emphasised that it is a small self-selecting sample. Though seven participants is not necessarily too small to establish broad themes (Guest et al., 2006; Isman et al., 2013), it is difficult to know whether the data corpus had reached a saturation point. It is also difficult to know how experiences and themes may have varied with more participants. It would be particularly interesting to conduct research with staff members who were new to this area of work; new staff were specifically excluded from taking part as we wanted to ensure that staff were able to confidently speak about using this somewhat infrequently used care pathway. It was felt that staff who had recently joined the hospice may not have had the opportunity to care for enough families within the

neonatal pathway to make sense of the experiences alongside their primary roles within the hospice. However, this perspective may help illuminate the experiences of early sense making of the role and how staff who are not overly experienced in the role manage the unique demands. This is particularly in light of findings that staff found earlier experiences within the pathway more difficult, particularly the first times they had experienced something.

Future Implications for Research and Clinical Practice

Findings from this research particularly highlight the organisational structures in place which staff identified as being helpful in managing the demands of work which can at times be challenging. It may be that results are reflective of a gold-standard in children's hospice care, and would be worth evaluating and disseminating more widely in the hospice community. The length of service for the participants is indicative of a workplace environment which works well and supports staff in managing their work on both practical and emotional levels, and would be worth evaluation in reinforcing best practice guidelines. Further research could also focus on evaluating the effectiveness of the individual structures identified, such as internal supervision, external supervision and team debriefs. Research could also seek to understand newer staff members' experiences within this pathway to help clarify if themes seen in the current study reflect the wider staff experiences at the hospices.

As noted, it would be interesting to investigate the construct of hardiness in this particular staff group as this could have implications for recruitment practices within both this and other children's hospice organisations. It is also possible that the lack of stress noted in the sample is related to the infrequency with which the care pathway is utilised; it would be worth conducting research into staff stress alongside an analysis of time spent within the different pathways of the children's hospice. It may be that the more positive,

enriching experiences seen in providing good palliative care with children, and the perceived rewards of the work are offsetting any of the more challenging aspects of working alongside and with an infant's deceased body in the neonatal pathway. Analysis of staff's attitudes towards death would also be an interesting avenue of research which could also help enhance the recruitment process within challenging environments such as these.

With the increasing use of 'cold' facilities in children's hospices and an expansion of staff's roles to encompass this specialist area of bereavement support, it is important to understand the needs of staff who provide this care in ensuring their wellbeing. This thesis represents a first step in establishing an evidence base in this area.

References

Abdel-Khalek, A. M. (2005). Death anxiety in clinical and non-clinical groups. *Death Studies, 29,* 251–259.

Abdollah, A., Abu Talib, M., Yaacob, S.N., & Ismail, Z. (2014). Hardiness as a mediator between perceived stress and happiness in nurses. *Journal of Psychiatric Mental Health Nursing, 21(9),* 789-796.

Baker, S. E. & Edwards, R. (2012). *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research.* Southampton, UK: ESRC National Centre for Research Methods, University of Southampton.

Bassett, J.F. (2007). Psychological defences against death anxiety: Integrating Terror Management Theory and Firestone's Separation Theory. *Death Studies, 31(8),* 727-750.

Becker, E. (1973). *The Denial of Death.* New York, NY: Free Press.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3(2),* 77-101.

Braun, V. & Clarke, V. (2013). *Successful Qualitative Research.* London UK: Sage.

Braun, V. and Clarke, V. (2014). What can thematic analysis offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-being*, 9.

Collins, H. (2010). *Creative Research: The Theory and Practice of Research for the Creative Industrie*s. Switzerland: AVA Publications.

Davies, R. (2005). Mothers' stories of loss: their need to be with their dying child and their child's body after death. *Journal of Child Healthcare, 9(4),* 288-300.

Denzin, N. K. & Lincoln, Y. S. (2011). *Handbook of Qualitative Research* (4th Ed) London, UK: Sage.

Doka, K.J. (1989). *Disenfranchised Grief: Recognizing Hidden Sorrow.* Lanham, MD: Lexington Books.

FlexMort (2017). CuddleCot™. Retrieved from: http://flexmort.com/cuddle-cots/

Fontana, A. & Frey, J.H. (2011). The interview: From neutral stance to political movement. N.K. Denzin, & Y.S. Lincoln (Eds), *Handbook of Qualitative Research (4th Ed)* . p. 695-727. London, UK: Sage.

Forrester, L. (2008). Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child. *International Journal of Palliative Nursing, 14(12),* 578-585.

Francis, J.J., Johnston, M., Robertson, Robertson, C., Glidewell, L., Entwistle, V.,… Grimshaw, J.M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Journal of Psychology & Health, 25(10),* 1229-1245.

Fugard, A. J. B. & Potts, H. W. W. (2015). Supporting thinking on sample sizes for thematic analyses: A quantitative tool. *International Journal of Social Research Methodology, 18,* 669-684.

Grbich, C. (2013). *Qualitative Data Analysis: An introduction.* London, UK: Sage.

Green, J. & Thorogood, N. (2004). *Qualitative Methods for Health Research.* London, UK: Sage.

Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The causes and consequences of a need for self-esteem: A terror management theory. In R. F. Baumeister (Ed.), *Public Self and Private Self* (pp. 189–212). New York, NY: Springer-Verlag.

Guba, E. G. (1990). The alternative paradigm dialog. In E. G. Guba (Ed.), *The Paradigm Dialog* (pp. 17-30). Newbury Park, CA: Sage.

Guba, E., & Lincoln, Y. (1989). *Fourth Generation Evaluation.* Newbury Park, CA :Sage.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 105-117). Thousand Oaks, CA: Sage.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods, 18*, 59–82.

Hill, R.C., Dempster, M., Donnelly, M., & McCorry, N.K. (2016). Improving the wellbeing of staff who work in palliative care settings: A systematic review of psychosocial interventions. *Palliative Medicine, 30(9),* 825-833.

Isman, E., Ekéus, C., & Berggren, V. (2013). Perceptions and experiences of female genital mutilation after immigration to Sweden: An explorative study. *Sexual & Reproductive Healthcare, 4,* 93–98.

Johnson, J.V., & Hall, E.M. (1988). Job strain, work place social support, and cardiovascular disease: A cross-sectional study of a random sample of Swedish working population. *American Journal of Public Health, 78,* 1336-1342.

Judkins, S. K. (2004). Stress among nurse managers: Can anything help? *Nurse Researcher, 12(2),* 58-70.

Judkins, S.K. & Rind, R. (2005). Hardiness, job satisfaction, and stress among home health nurses. *Home Health Care Management & Practice, 17(2),* 113-118.

Kaplan, L.J. (2000). Toward a model of caregiver grief: Nurses' experiences of treating dying children. *Omega, 41,* 187-206.

Kellehear, A. (2005). *Compassionate Cities: Public Health and End-of-life Care.* London, UK: Routledge.

Lawler, J. (1991). *Behind the Screens: Nursing, Somology, and the Problem of the Body.* Melbourne, Australia: Churchill Livingstone.

Lehto, R.H. & Stein, K.F. (2009). Death anxiety: An analysis of an evolving concept. *Research & Theory for Nursing Practice, 23(1),* 23-41.

Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry.* London, UK: Sage.

Lyons, E. & Coyle, A. (2007). *Analysing Qualitative Data in Psychology*. London, UK: Sage.

Morrow, S. (2007). Qualitative research in counselling psychology: Conceptual foundations. *The Counseling Psychologist, 35(2),* 209-235.

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

Mason, J. (1996). *Qualitative Research*. London, UK: Sage.

Mays, N. & Pope, C. (1995). Qualitative research: Rigour and qualitative research. *British Medical Journal, 311*, 109-117.

McGuire, W. J. (1983). A contextual theory of knowledge: Its implications for innovation and reform in psychological research. *Advances in Experimental Social Psychology, 16*, 1-47.

Mikkelsen, B. (2005) *Methods for Development Work and Research A New Guide for Practitioners* (2nd Ed). London, UK: Sage.

Neuman, L. W. (2000). *Social Research Methods: Qualitative and Quantitative Approaches* (4th Ed.). Boston, MA: Allyn and Bacon.

O'Gorman, K. & MacIntosh, R. (2014). *Research Methods for Business & Management.* Oxford, UK: Goodfellows.

Owen, R. (2000). Relieving stress in palliative care staff. *Palliative Care Today, 9(1),* 4–5.

Patton, M.Q. (2002). *Qualitative Research & Evaluation Methods* (3rd Ed). Thousand Oaks, CA: Sage.

Quested, B. & Rudge, T. (2003). Nursing care of dead bodies: A discursive analysis of last offices. *Journal of Advanced Nursing, 41(6),* 553-560.

Rubin, H. R. & Rubin. I. S. (2011). *Qualitative Interviewing: The Art of Hearing Data*. London, UK: Sage.

Seale, C. (1999). *The Quality of Qualitative Research*. London, UK: Sage.

Shucksmith, J., Carlebach, S., & Whittaker, V. (2013). Dying: Discussing and planning for the end of life. *British Social Attitudes, 30,* 1-22.

Sleeter, C. E. (2001). Epistemological diversity in research on preservice teacher preparation for historically underserved children. *Review of Research in Education, 25,* 209-250.

Tebes, J.K. (2005). Community science, philosophy of science, and the practice of research. *American Journal of Community Psychology, 35(3-4),* 213-230.

Vachon, M.L.S. (1987). *Occupational Stress in the Care of the Critically Ill, Dying and the Bereaved.* New York, NY: Hemisphere.

van Servellen, G., Topf, M., & Leake, B. (1994). Personality hardiness, work-related stress, and health in hospital nurses. *Hospital Topics, 72(2),* 34-39.

Wakefield, A. (2000). Nurses' responses to death and dying: a need for relentless self-care. *Journal of Palliative Nursing, 6(5),* 245-251.

Wright, T. F., Blance, C. F., Ralph J., & Luterman, A. (1993). Hardiness, stress, and burnout among intensive care nurses. *Journal of Burn Care & Rehabilitation, 14(3),* 76-81.

Zimmerman, C. (2012). Acceptance of dying: A discourse analysis of palliative care literature. *Social Science & Medicine, 75,* 217-224.

Zimmerman, C. & Rodin, G. (2004). The denial of death thesis: Sociological critique and implications for palliative care. *Palliative Medicine, 18,* 121-128.

List of Appendices

Appendix A: MMAT Tool

Appendix B: Palliative & Supportive Care Submission Guidelines

Appendix C: Qualitative Health Research Submission Guidelines

Appendix D: Feedback on Thesis Proposal

Appendix E: Approval from FMH Research Ethics Committee

Appendix F: Approval letter from hospice Clinical Governance Committee

Appendix G: Amendment approval from FMH Research Ethics Committee

Appendix H: Participant Information Sheet

Appendix I: Consent Form

Appendix J: Expression of Interest Form

Appendix K: Confirmation of Accuracy Sheet

Appendix L: Demographic Information Sheet

Appendix M: Preliminary Topic Guide

Appendix N: Interview Schedule

Appendix O: Example Transcript and Codes

Appendix P: Example of Initial Coding Groups

Appendix Q: Reflections on Theme Review

Appendix A – MMAT Guidelines

McGill

Mixed Methods Appraisal Tool (MMAT) – Version 2011
For dissemination, application, and feedback: Please contact pierre.pluye@mcgill.ca, Department of Family Medicine, McGill University, Canada.

The MMAT is comprised of two parts (see below): criteria (Part I) and tutorial (Part II). While the content validity and the reliability of the pilot version of the MMAT have been examined, this critical appraisal tool is still in development. Thus, the MMAT must be used with caution, and users' feedback is appreciated. Cite the present version as follows.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Retrieved on [date] from http://mixedmethodsappraisaltoolpublic.pbworks.com. Archived by WebCite® at http://www.webcitation.org/5tTRTc9yJ

Purpose: The MMAT has been designed for the appraisal stage of complex systematic literature reviews that include qualitative, quantitative and mixed methods studies (mixed studies reviews). The MMAT permits to concomitantly appraise and describe the methodological quality for three methodological domains: mixed, qualitative and quantitative (subdivided into three sub-domains: randomized controlled, non-randomized, and descriptive). Therefore, using the MMAT requires experience or training in these domains. E.g., MMAT users may be helped by a colleague with specific expertise when needed. The MMAT allows the appraisal of most common types of study methodology and design. For appraising a qualitative study, use section 1 of the MMAT. For a quantitative study, use section 2 or 3 or 4, for randomized controlled, non-randomized, and descriptive studies, respectively. For a mixed methods study, use section 1 for appraising the qualitative component, the appropriate section for the quantitative component (2 or 3 or 4), and section 5 for the mixed methods component. For each relevant study selected for a systematic mixed studies review, the methodological quality can then be described using the corresponding criteria. This may lead to exclude studies with lowest quality from the synthesis, or to consider the quality of studies for contrasting their results (e.g., low quality vs. high).

Scoring metrics: For each retained study, an overall quality score may be not informative (in comparison to a descriptive summary using MMAT criteria), but might be calculated using the MMAT. Since there are only a few criteria for each domain, the score can be presented using descriptors such as *, **, ***, and ****. For qualitative and quantitative studies, this score can be the number of criteria met divided by four (scores varying from 25% (*) -one criterion met- to 100% (****) -all criteria met-). For mixed methods research studies, the premise is that the overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components. The score is 25% (*) when $QUAL=1$ or $QUAN=1$ or $MM=0$; it is 50% (**) when $QUAL=2$ or $QUAN=2$ or $MM=1$; it is 75% (***) when $QUAL=3$ or $QUAN=3$ or $MM=2$; and it is 100% (****) when $QUAL=4$ and $QUAN=4$ and $MM=3$ (QUAL being the score of the qualitative component; QUAN the score of the quantitative component; and MM the score of the mixed methods component).

Rationale: There are general criteria for planning, designing and reporting mixed methods research (Creswell and Plano Clark, 2010), but there is no consensus on key specific criteria for appraising the methodological quality of mixed methods studies (O'Cathain, Murphy and Nicholl, 2008). Based on a critical examination of 17 health-related systematic mixed studies reviews, an initial 15-criteria version of MMAT was proposed (Pluye, Gagnon, Griffiths and Johnson-Lafleur, 2009). This was pilot tested in 2009. Two raters assessed 29 studies using the pilot MMAT criteria and tutorial (Pace, Pluye, Bartlett, Macaulay et al., 2010). Based on this pilot exercise, it is anticipated that applying MMAT may take on average 15 minutes per study (hence efficient), and that the Intra-Class Correlation might be around 0.8 (hence reliable). The present 2011 revision is based on feedback from four workshops, and a comprehensive framework for assessing the quality of mixed methods research (O'Cathain, 2010).

Conclusion: The MMAT has been designed to appraise the *methodological quality* of the studies retained for a systematic mixed studies review, not the quality of their *reporting* (writing). This distinction is important, as good research may not be 'well' reported. If reviewers want to genuinely assess the former, companion papers and research reports should be collected when some criteria are not met, and authors of the corresponding publications should be contacted for additional information. Collecting additional data is usually necessary to appraise *qualitative research and mixed methods studies*, as there are no uniform standards for reporting study characteristics in these domains (www.equator-network.org), in contrast, e.g., to the CONSORT statement for reporting randomized controlled trials (www.consort-statement.org).

Authors and contributors: Pierre Pluye[1], Marie-Pierre Gagnon[2], Frances Griffiths[3] and Janique Johnson-Lafleur[1] proposed an initial version of MMAT criteria (Pluye et al., 2009). Romina Pace[1] and Pierre Pluye[1] led the pilot test. Gillian Bartlett[1], Belinda Nicolau[4], Robbyn Seller[1], Justin Jagosh[1], Jon Salsberg[1] and Ann Macaulay[1] contributed to the pilot work (Pace et al., 2010). Pierre Pluye[1], Émilie Robert[5], Margaret Cargo[6], Alicia O'Cathain[7], Frances Griffiths[3], Felicity Boardman[3], Marie-Pierre Gagnon[2], Gillian Bartlett[1], and Marie-Claude Rousseau[8] contributed to the present 2011 version.

Affiliations: 1. Department of Family Medicine, McGill University, Canada; 2. Faculté des sciences infirmières, Université Laval, Canada; 3. Warwick Medical School, University of Warwick, UK; 4. Faculty of Dentistry, McGill University, Canada; 5. Centre de recherche du CHUM, Université de Montréal, Canada; 6. School of Health Sciences, University of South Australia, Australia; 7. Medical Care Research Unit, ScHARR, University of Sheffield, UK; 8. INRS-Institut Armand Frappier, Laval, Canada

PART I. MMAT criteria & one-page template (to be included in appraisal forms)

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	• Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

PART II. MMAT tutorial

Types of mixed methods study components or primary studies	Methodological quality criteria
1. Qualitative Common types of qualitative research methodology include: A. Ethnography The aim of the study is to describe and interpret the shared cultural behaviour of a group of individuals. B. Phenomenology The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals. C. Narrative The study analyzes life experiences of an individual or a group. D. Grounded theory Generation of theory from data in the process of conducting research (data collection occurs first). E. Case study In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country. F. Qualitative description There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive). Key references: Creswell, 1998; Schwandt, 2001; Sandelowski, 2010.	**1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?** E.g., consider whether (a) the selection of the participants is clear, and appropriate to collect relevant and rich data; and (b) reasons why certain potential participants chose not to participate are explained.
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)? E.g., consider whether (a) the method of data collection is clear (in depth interviews and/or group interviews, and/or observations and/or documentary sources); (b) the form of the data is clear (tape recording, video material, and/or field notes for instance); (c) changes are explained when methods are altered during the study; and (d) the qualitative data analysis addresses the question.
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? * E.g., consider whether the study context and how findings relate to the context or characteristics of the context are explained (how findings are influenced by or influence the context). "For example, a researcher wishing to observe care in an acute hospital around the clock may not be able to study more than one hospital. (…) Here, it is essential to take care to describe the context and particulars of the case [the hospital] and to flag up for the reader the similarities and differences between the case and other settings of the same type" (Mays & Pope, 1995). The notion of context may be conceived in different ways depending on the approach (methodology) tradition.
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants? * E.g., consider whether (a) researchers critically explain how findings relate to their perspective, role, and interactions with participants (how the research process is influenced by or influences the researcher); (b) researcher's role is influential at all stages (formulation of a research question, data collection, data analysis and interpretation of findings); and (c) researchers explain their reaction to critical events that occurred during the study. The notion of reflexivity may be conceived in different ways depending on the approach (methodology) tradition. E.g., "at a minimum, researchers employing a generic approach [qualitative description] must explicitly identify their disciplinary affiliation, what brought them to the question, and the assumptions they make about the topic of interest" (Caelli, Ray & Mill, 2003, p. 5).

*See suggestion on the MMAT wiki homepage (under '2011 version'): Independent reviewers can establish a common understanding of these two items prior to beginning the critical appraisal.

Types of mixed methods study components or primary studies	Methodological quality criteria
2. Quantitative randomized controlled (trials) Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers). Key references: Higgins & Green, 2008; Porta, 2008; Oxford Center for Evidence based medicine, 2009.	**2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?** In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance, and researchers describe how the randomization schedule is generated. "A simple statement such as 'we randomly allocated' or 'using a randomized design' is insufficient". *Simple randomization:* Allocation of participants to groups by chance by following a predetermined plan/sequence. "Usually it is achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer". *Sequence generation:* "The rule for allocating interventions to participants must be specified, based on some chance (random) process". Researchers provide sufficient detail to allow a readers' appraisal of whether it produces comparable groups. E.g., blocked randomization (to ensure particular allocation ratios to the intervention groups), or stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics).
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? *The allocation concealment protects assignment sequence until allocation.* E.g., researchers and participants are unaware of the assignment sequence up to the point of allocation. E.g., group assignment is concealed in opaque envelops until allocation. *The blinding protects assignment sequence after allocation.* E.g., researchers and/or participants are unaware of the group a participant is allocated to during the course of the study.
	2.3. Are there complete outcome data (80% or above)? E.g., almost all the participants contributed to almost all measures.
	2.4. Is there low withdrawal/drop-out (below 20%)? E.g., almost all the participants completed the study.

Types of mixed methods study components or primary studies	Methodological quality criteria
3. Quantitative non-randomized Common types of design include (A) non-randomized controlled trials, and (B-C-D) observational analytic study or component where the intervention/exposure is defined/assessed, but not assigned by researchers. A. Non-randomized controlled trials The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups.	**3.1. Are participants (organizations) recruited in a way that minimizes selection bias?** At recruitment stage: For cohort studies, e.g., consider whether the exposed (or with intervention) and non-exposed (or without intervention) groups are recruited from the same population. For case-control studies, e.g., consider whether same inclusion and exclusion criteria were applied to cases and controls, and whether recruitment was done independently of the intervention or exposure status. For cross-sectional analytic studies, e.g., consider whether the sample is representative of the population.

B. Cohort study
    Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal).
 	
C. Case-control study
    Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective).
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?
	
	At data collection stage:
	
	E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) the measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.
	
	For non-randomized controlled trials, the intervention is assigned by researchers, and so consider whether there was absence/presence of a contamination. E.g., the control group may be indirectly exposed to the intervention through family or community relationships.

D. Cross-sectional analytic study At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population sub-groups according to the presence/absence (or level) of the intervention/exposure. Key references for observational analytic studies: Higgins & Green, 2008; Wells, Shea, O'Connell, Peterson, et al., 2009.	**3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?** At data analysis stage: For cohort, case-control and cross-sectional, e.g., consider whether (a) the most important factors are taken into account in the analysis; (b) a table lists key demographic information comparing both groups, and there are no obvious dissimilarities between groups that may account for any differences in outcomes, or dissimilarities are taken into account in the analysis.
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

Types of mixed methods study components or primary studies	Methodological quality criteria

4. Quantitative descriptive studies
 	
Common types of design include single-group studies:
 	
A. Incidence or prevalence study without comparison group
  In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed).
 	
B. Case series
  A collection of individuals with similar characteristics are used to describe an outcome.
 	
C. Case report
  An individual or a group with a unique/unusual outcome is described in details.
 	
Key references: Critical Appraisal Skills Programme, 2009; Draugalis, Coons & Plaza, 2008.
	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?
	
	E.g., consider whether (a) the source of sample is relevant to the population under study; (b) when appropriate, there is a standard procedure for sampling, and the sample size is justified (using power calculation for instance).

	4.2. Is the sample representative of the population understudy? E.g., consider whether (a) inclusion and exclusion criteria are explained; and (b) reasons why certain eligible individuals chose not to participate are explained.
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.
	4.4. Is there an acceptable response rate (60% or above)? The response rate is not pertinent for case series and case report. E.g., there is no expectation that a case series would include all patients in a similar situation.

Types of mixed methods study components or primary studies	Methodological quality criteria
5. Mixed methods Common types of design include: A. Sequential explanatory design The quantitative component is followed by the qualitative. The purpose is to explain quantitative results using qualitative findings. E.g., the quantitative results guide the selection of qualitative data sources and data collection, and the qualitative findings contribute to the interpretation of quantitative results. B. Sequential exploratory design The qualitative component is followed by the quantitative. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the qualitative findings inform the quantitative data collection, and the quantitative results allow a generalization of the qualitative findings. C. Triangulation design The qualitative and quantitative components are concomitant. The purpose is to examine the same phenomenon by interpreting qualitative and quantitative results (bringing data analysis together at the interpretation stage), or by integrating qualitative and quantitative datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). D. Embedded design The qualitative and quantitative components are concomitant. The purpose is to support a qualitative study with a quantitative sub-study (measures), or to better understand a specific issue of a quantitative study using a qualitative sub-study, e.g., the efficacy or the implementation of an intervention based on the views of participants. Key references: Creswell & Plano Clark, 2007; O'Cathain, 2010.	**5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?** E.g., the rationale for integrating qualitative and quantitative methods to answer the research question is explained. **5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?** E.g., there is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration. **5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?**

References

- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as Mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods, 2(2)*, 1-23.
- Creswell, J., & Plano Clark, V. (2007). *Designing and conducting mixed methods research*. London: Sage.
- Creswell, J. (1998). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks: Sage.
- Critical Appraisal Skills Programme (2009). CASP appraisal tools. Retrieved on August 26, 2009 from: *www.phru.nhs.uk/pages/PHD/resources.htm*
- Draugalis, J.R., Coons, S.J., & Plaza, C.M. (2008). Best practices for survey research reports: a synopsis for authors and reviewers. *American Journal of Pharmaceutical Education, 72(1)*, e11.
- Higgins, J.P.T. & Green, S. (2008). *Cochrane Handbook for Systematic Reviews of Interventions* - Version 5.0.1 [updated September 2008]. The Cochrane Collaboration. Retrieved on August 26, 2009 from www.cochrane-handbook.org
- Mays, N., & Pope, C. (1995). Qualitative Research: Rigour and qualitative research. *British Medical Journal, 311(6997)*, 109-112.
- O'Cathain, A., Murphy, E. & Nicholl, J. (2008). The quality of mixed methods studies in health services research. *Journal of Health Services Research and Policy, 13(2)*, 92-98.
- O'Cathain, A. (2010). Assessing the quality of mixed methods research: Towards a comprehensive framework. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research (2nd edition)* (pp. 531-555). Thousand Oaks: Sage.
- Pace, R., Pluye, P., Bartlett, G., Macaulay, A., Salsberg, J., Jagosh, J., & Seller, R. (2010). *Reliability of a tool for concomitantly appraising the methodological quality of qualitative, quantitative and mixed methods research: a pilot study*. 38th Annual Meeting of the North American Primary Care Research Group (NAPCRG), Seattle, USA.
- Pluye, P., Gagnon, M.P., Griffiths, F. & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies, 46(4)*, 529-46.
- Oxford Center for Evidence Based Medicine (2009). Levels of evidence. Retrieved on July 7, 2009 from www.cebm.net/levels_of_evidence.asp
- Porta, M. (2008). *A Dictionary of Epidemiology*. New York: Oxford University Press.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health, 33(1)*, 77-84.
- Schwandt, T. (2001). *Dictionary of qualitive inquiry*. Thousand Oaks: Sage.
- Wells, G.A., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2009). *The Newcastle-Ottawa Scale (NOS) for assessing the quality of non-randomised studies in meta-analyses*. The Cochrane Non-Randomized Studies Method Group. Retrieved on July 7, 2009 from www.ohri.ca/programs/clinical_epidemiology/oxford.htm

<center>**Appendix B – Palliative & Supportive Care Submission Guidelines**</center>

Instructions for contributors
Editorial Aims and Scope

Palliative & Supportive Care publishes papers on the psychiatric, psychosocial, spiritual, existential, ethical, philosophical, and humanities aspects of palliative and supportive care. Papers on psychiatric disorders and their management in the palliative care setting, including but not limited to depression, delirium, anxiety, and posttraumatic stress disorder and bereavement are invited. Evolving constructs of particular relevance to the interface of psychiatry/psychology and palliative medicine, such as demoralization, meaning, dignity, hopelessness, will to live, suffering, and developmental growth at the end of life are also a major focus of this journal. Research focusing on these issues, including epidemiology, diagnostic screening, assessment, management, and intervention drug and psychotherapy trials, are also addressed. In addition, the journal provides a forum for the study of psychosocial and sociocultural matters such as caregiver burden, health care provider burnout, counseling interventions, the impact of psychosocial factors related to pain and physical symptom control, and communication issues.

ORIGINAL ARTICLES/ORIGINAL RESEARCH ARTICLES
These articles represent well designed quantitative, qualitative or mixed methods research studies that present new information that makes a substantial contribution to the body of knowledge on the subject. Original research manuscript must contain a Title page, an Abstract (with the headings: Objectives, Methods, Results, Significance of Results – 500 word limit) and be organized into the following major sections: Introduction, Methods, Results, Discussion, Disclosures and Acknowledgments, and References (word limit 4,000 words not including references, Tables and Figures)

REVIEW
Review articles describe and evaluate previously published material in order to synthesize or describe the state of the science or suggest new approaches or ideas relevant to important topics in psychosocial palliative care. The Journal accepts both systematic and narrative reviews of high quality. Word limit: 5000 words, not including references, tables or figures. An abstract of the same format as an Original Article is required (500 word limit).

CASE REPORTS
Case reports describing a single case or case series which describes a novel, relevant or unusual presentation of a clinical problem that is important to make the field aware of are accepted for publication. An abstract with the journal standard headings is suggested (500 word limit) case Reports have a 1500 word limit excluding references, tables and figures.
PERSONAL ESSAYS
Personal essays are creative original essays by clinicians , researchers, patients or relatives that are compelling personal experiences or insights into clinical practice or the experience of caring for patients in the supportive and palliative care setting (1500 word limit excluding references)
EDITORIALS/GUEST EDITORIALS
Scholarly opinions on scientific, clinical or policy aspects of palliative and supportive care . They can be related to papers which have appeared or currently appear in an issue of Palliative and Supportive Care.No Abstract.(1500 word limit excluding references)
LETTERS TO THE EDITOR

Letters to the editor are academically oriented letters commenting on papers appearing in Palliative and Supportive Care 500 word limit, excluding tables or figures.

POETRY

Poems related to the themes of psychosocial existential and spiritual aspects of palliative care. (750 word limit, exceptions made)

Manuscript Submission and Review

All manuscripts must be submitted through the Journal's online submission platform, ScholarOne Manuscripts. When submitting articles online, authors are required to submit a separate abstract (utilizing specific abstract headings), the full manuscript (including the elements and order described in Instructions for Authors, e.g., title page, abstract, etc.), as well as an optional cover letter. Each manuscript will normally be reviewed by at least two referees with relevant scientific experience. Authors may suggest appropriate reviewers, but final selection of referees will be made by the Editor. Reviewers are asked to evaluate manuscripts for their scientific merit and clarity of presentation.

Manuscript Preparation and Style

Manuscripts must be in English and double-spaced. Numbers should be spelled out when they occur at the beginning of a sentence; use Arabic numerals elsewhere. Abbreviations should be used sparingly and nonstandard abbreviations should be defined at their first occurrence. Metric system (SI) units should be used. Manuscripts that do not conform to the style of **Palliative & Supportive Care** will be returned without review.

MANUSCRIPT ELEMENTS AND ORDER.

Unless there are obvious and compelling reasons for variation (e.g. review articles, short communications), manuscripts should be organized as follows:

Title page. This is page 1. The title should be concise, informative, and free of abbreviations, chemical formulae, technical jargon, and esoteric terms. This page should include (a) the article's full title, (b) names and affiliations of all authors, (c) the name, mailing address, email address, and telephone number of the corresponding author, (d) the address for reprint requests if different from that of the corresponding author, (e) a short title of 50 characters or less, and (f) a list of the number of manuscript pages, number of tables, and number of figures.

Abstract and keywords page. This is page 2 and should include (a) the article's full title, (b) an abstract of no more than 300 words, and (c) up to 5 keywords or phrases that reflect the content and major thrust of the article. The abstract should give a succinct account of the article contents utilizing these specific abstract headings: Objectives; Methods; Results; Significance of Results.

Introduction. This section begins on page 3 and should clearly state the objective of the research in the context of previous work bearing directly on the subject. An extensive review of the literature is not usually appropriate.

Methods. This section should be brief but provide sufficient information to permit others to replicate the study. Pertinent details of species, apparatus and equipment, procedures and experimental design should be described.

All experiments involving human subjects must be conducted in accordance with principles embodied in the Declaration of Helsinki (Code of Ethics of the World Medical Association). Experiments involving animal subjects must conform to the principles regarding the care and use of animals adopted by the American Physiological Society and the Society for Neuroscience. The editor may refuse papers that provide insufficient evidence of adherence to these principles.

Results. The results should be presented clearly and concisely, using figures and tables to summarize or illustrate the important findings. Quantitative observations are often more effectively displayed in graphs than in tables.

Discussion. The discussion should summarize the major findings and explain their significance in terms of the study's objectives and relationship to previous, relevant work.

This section should present compact, clearly developed arguments rather than wide-ranging speculation or uncritical collation of earlier reports.

Acknowledgments. Use a separate page to recognize the contributions of individuals and supporting institutions.

References. In the text, references should be cited as follows:

as shown by Cella and Tusky (1990)

(Bloom et al., 2000)

(Cella & Tusky, 1990; Bloom et al., 2000)

The alphabetical list of references begins a new page, and must be typed double-spaced. Each in-text citation must have a corresponding reference and vice versa. List works by different authors who are cited within the same parentheses in chronological order, beginning with the earlier work. Journal titles should not be abbreviated. Only published articles and articles in press should appear in this list. Responsibility for the accuracy of references cited lies with the authors. Brief examples:

Journal article

Cella, D.F. & Tusky, D.S. (1990). Measuring quality of life today: Methodological aspects. **Oncology**, 4 , 29–38.

Book

Tompar-Tiu, A. & Sustento-Seneriches, J. (1995). **Depression and Other Mental Health Issues: The Filipino American Experience**. San Francisco: Jossey-Bass.

Chapter in an edited book

Karnofsky, D.A. & Burchenal, J.H. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In**Evaluation of Chemotherapeutic Agents in Cancer**, Macleod, C.M. (ed.), pp. 191 –205. New York: Columbia University Press.

For more than one work by the same author(s) published in the same year, use (Jones, 1986 a , 1986 b) in text and likewise in the reference section.

Tables

Tables may be submitted as Word or Excel files. Tables should be numbered consecutively with Arabic numerals. A short explanatory title and column headings should make the table intelligible without reference to the text.

Figures and Legends

Figures may be submitted as TIFF or EPS files at 300pi or higher. The number of figures should be the minimum necessary to make the essential points of the paper. Diagrams and illustrations must have a professional appearance.

Copyediting and Page Proofs

The publisher reserves the right to copyedit manuscripts to conform to the style of **Palliative & Supportive Care.** The corresponding author will receive page proofs for final proofreading. No rewriting of the final accepted manuscript is permitted at the proof stage, and substantial changes may be charged to the authors.

Author Language Services

Cambridge University Press recommends that authors have their manuscripts checked by a native English-language speaker before submission; this will ensure that submissions are judged during peer review exclusively on academic merit. We list a number of third-party services specializing in language editing and/or translation, and suggest that authors contact as appropriate. Use of any of these services is voluntary, and at the author's own expense.

Originality and Copyright

To be considered for publication in **Palliative & Supportive Care** a manuscript cannot have been published previously, nor can it be under review for publication elsewhere. Papers with multiple authors are reviewed with the assumption that all authors have approved the

ubmitted manuscript and concur in its submission to **Palliative & Supportive Care**. A Transfer of Copyright Agreement must be executed before an article can be published. Government authors whose articles were created in the course of their employment must so

certify in lieu of copyright transfer. Authors are responsible for obtaining written permission from the copyright owners to reprint any previously published material included in their article.

Appendix C – Qualitative Health Research Submission Guidelines

1. Article Types
>   1.1 What type of articles will QHR accept?

2. Editorial Policies
>   2.1 Peer review policy
>   2.2 Authorship
>   2.3 Acknowledgements
>   2.4 Funding
>   2.5 Declaration of conflicting interests
>   2.6 Research ethics and patient consent
>   2.7 Clinical trials
>   2.8 Reporting guidelines
>   2.9 Data

3. Publishing Policies
>   3.1 Publication ethics
>   3.2 Contributor's publishing agreement
>   3.3 Open access and author archiving
>   3.4 Permissions

4. Preparing your Manuscript
>   4.1 Article format
>   4.2 Word processing formats
>   4.3 Artwork, figures and other graphics
>   4.4 Supplementary material
>   4.5 Journal layout
>   4.6 Reference style
>   4.7 English language editing services
>   4.8 Review Criteria

5. Submitting your Manuscript
>   5.1 How to submit your manuscript
>   5.2 Title, keywords and abstracts
>   5.3 Corresponding author contact details

6. On Acceptance and Publication
>   6.1 Fees
>   6.2 SAGE Production
>   6.3 Access to your published article
>   6.4 Online First publication
>   6.5 Open Access and SAGE Choice

7. Additional information

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/qhr to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your

1. Article types

Each issue of QHR provides readers with a wealth of information — book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.1 What types of articles will QHR accept?

QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main QHR webpage.
- Search the QHR journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- QHR is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Book Review Section: *Qualitative Health Research* includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

2. Editorial policies

2.1 Peer review policy

QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are initially reviewed by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Ensure your manuscript does not contain any author identifying information. Please refer to the editorial on blinding found in the Nov 2014 issue: http://qhr.sagepub.com/content/24/11/1467.full.

QHR maintains a transparent review system, meaning that all reviews, once received, are then forwarded to the author(s) as well as to ALL reviewers.

Peer review takes an average of 6–8 weeks, depending on reviewer response.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.
The list of authors should include all those who can legitimately claim authorship. This is all authors who:

(i)   Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
(ii) Drafted the article or revised it critically for important intellectual content,
(iii) Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

When a large, multicenter group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section.
Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Writing assistance

Individuals who provided writing assistance, e.g., from a specialist communications company, do not qualify as authors and should only be included in the Acknowledgements section.
Authors must disclose any writing assistance — including the individual's name,

company and level of input — and identify the entity that paid for this assistance.

It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately from the main text to facilitate anonymous peer review.

2.4 Funding

QHR requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page to confirm the format of the acknowledgement text in the event of funding. Otherwise, state that: This research received no specific grant from any funding agency in the public, commercial, or not-for- profit sectors.

2.5 Declaration of conflicting interests

It is the policy of QHR to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a "'Declaration of Conflicting Interests" statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that "The Author(s) declare(s) that there is no conflict of interest."

For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

In terms of patient privacy, authors are required to follow the ICMJE Recommendations for the Protection of Research Participants. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

2.7 Clinical trials

QHR conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

QHR requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third- party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. [The editor(s) may consider limited embargoes on proprietary data.] The editor(s) [can/will] also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at vshannonqhr@gmail.com.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

QHR and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarized other work, or included third-party copyright material without permission, or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive license agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and license to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more

information please visit [our Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

3.3 Open access and author archiving

QHR offers optional open access publishing via the SAGE Choice program. For more information please visit [the SAGE Choice website](#). For information on funding body compliance, and depositing your article in repositories, please [visit SAGE Publishing Policies](#) on our Journal Author Gateway.

3.4 Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit [our Frequently Asked Questions](#) on [the SAGE Journal Author Gateway](#).

4. Preparing your manuscript

4.1 Article Format (*see previously published articles in QHR for style*):
- *Title page:* Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- *Blinding:* Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- *Abstract:* Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- *Length:* QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- *Methods:* QHR readership is sophisticated; excessive details not required.
- *Ethics:* Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- *Results:* Rich and descriptive; theoretical; linked to practice if possible.
- *Discussion:* Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- *References:* APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:
- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics
- Figures: Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e., INSERT TABLE 1 HERE).
- Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.

- TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
- Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least **300 dpi** (dots per inch). Line art should be supplied with a minimum resolution of **800 dpi**.
- Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.

- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplementary material

This journal is able to host additional materials online (e.g., datasets, podcasts, videos, images, etc.) alongside the full-text of the article. These will be subjected to peer-review alongside
the article.

Supplementary files will be uploaded as supplied. They will not be checked for accuracy, copyedited, typeset or proofread. The responsibility for scientific accuracy and file functionality remains with the author(s). SAGE will only publish supplementary material subject to full copyright clearance. This means that if the content of the file is not original to the author, then the author will be responsible for clearing all permissions prior to publication. The author will be required to provide copies of permissions and details of the correct copyright acknowledgement.

4.5 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at http://www.apa.org/, or search the Internet for "APA format."

4.6 Reference style

QHR adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.7 English language editing services

Articles must be professionally edited; this is the responsibility of the author. Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE's Language Services.

4.8 Review Criteria

Before submitting the manuscript, authors should have their manuscript pre-reviewed using the following QHR criteria:

1. Importance of submission: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?

2. Theoretical orientation and evaluation: Is it theoretically clear and coherent? Is there logical progression throughout?

3. Methodological assessment: Appropriate to question and/or aims? Approach logically articulated? Clarity in design and presentation? Data adequacy and appropriateness? Evidence of rigor?

---

4. Ethical Concerns (Including IRB approval and consent):

---

5. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory? Relevant to practice/discipline?

---

6. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory?

---

7. Discussion: Results linked to literature? Contribution of research clear? Relevant to practice/discipline?

---

8. Manuscript style and format: Please evaluate writing style: Length (as short as possible], organization, clarity, grammar, appropriate citations, etc.); presentation of diagrams/illustrations?

5. Submitting your manuscript

5.1 How to submit your manuscript
QHR is hosted on SAGE Track, a web-based online submission and peer review system powered by ScholarOne Manuscripts.™ Visit http://mc.manuscriptcentral.com/qhr to login and submit your article online. Each component of the manuscript is uploaded separately: Title page, main document, tables, figures, supplemental material.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts
Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on How to Help Readers Find Your Article in the SAGE Journal Author Gateway on how best to title your article, write your abstract and select your keywords.

5.3 Corresponding author contact details
Provide full contact details of the corresponding author including email, mailing address and phone number. Academic affiliations are required for all co-authors. Present these details on the title page, separate from the article main text, to facilitate anonymous peer review.

6. On acceptance and publication

6.1 Fees

There are no fees to submit or publish, unless an author chooses to publish with open- access. See "Open Access and SAGE Choice" below. Fees for color reproduction of figures *in print* may also apply.

6.2 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author to make
final corrections and should be returned promptly.

6.3 Access to your published article

SAGE provides authors with online access to their final article. There is no set time frame when an article will be assigned to an issue.

6.4 OnlineFirst publication

OnlineFirst allows final revision articles (completed article in queue for assignment to an upcoming issue) to be published online prior to their inclusion in a final print journal issue, which significantly reduces the lead time between submission and publication. Articles published OnlineFirst are assigned a DOI number, but no volume/issue/page number information. Articles will be searchable in PubMed but the citation will not appear with volume/page number information until officially published in an issue. For more information, please visit our OnlineFirst Fact Sheet.

6.5 Open Access and SAGE Choice

Articles accepted in QHR have the option to be published as open access after payment of an article processing charge (APC) paid by either the funder or author. Authors wishing to publish open access should contact openaccess@sagepub.com to make the request. Read SAGE Choice FAQs here.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the QHR editorial office as follows:

Vanessa Shannon, Managing Editor, vshannonqhr@gmail.com

Appendix D – Feedback on Thesis Proposal

UNIVERSITY OF EAST ANGLIA ClinPsyD
FEEDBACK SHEET FOR ACADEMIC WORK - Clinical Psychology

TRAINEE: Meghan Waugh   **Date Submitted: 7 July 2015**

MARKER: Judith Young   **Date Marked: 8 August 2015**

Thesis Proposal:

TITLE: The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at ███████████████

AGREED MARK: 57   **PASS**

DETAILED COMMENTS:

GENERAL ORIENTATION (what is the context for the study and why is it interesting/clinically relevant?)

Unique facilities and services offered at ████████ and the studies on the use of cold bedroom facilities are well described. Research on emotional distress for the staff who care for dying infants and young children are briefly reviewed although not analysed in depth.

BACKGROUND AND INTRODUCTION (provides a review of relevant and contemporary literature, highlights gaps in existing research, provides a coherent theoretical framework for the study)

You highlight a gap in the literature, identifying a novel area for research – well done.

While it is helpful to have some contextual details, this level of detail of local information is probably more appropriate for an SRP proposal. A thesis proposal needs to be positioned within a clear theoretical framework. This is somewhat lacking and would need to be addressed in any final write up. What theoretical frameworks can you refer to (an example could be loss and bereavement) in order to orientate yourself and the reader to this research? It will be important for you to address this at an early stage in discussions with your supervisor and later in the thesis portfolio.

RESEARCH QUESTIONS/HYPOTHESES (clear and appropriate questions/hypotheses which follow from the background and which are answerable)

These require some further definition. It is unclear whether you are considering the experiences of any families referred to ██████ from NICU or only those that use the cold bedroom.   Given the lack of theoretical underpinning in the introduction (for example a psychological model of staff stress and support), qu 3 reads more like a service evaluation question than a research question.

DESIGN (clear description of research design which is appropriate for the question)

Is the focus group part of the study, if so what details can you provide about this methodological approach? Will the focus group contain the same participants to the interviews and if so what impact might this have? Will you carry out the focus group at a different ██████ service to the interviews? This needs clarification. Have you considered an ethics application that would propose the review of the semi- structured interview after 2 participants complete, and if no changes made, to include this data?

PARTICIPANTS (clearly described inclusion/exclusion criteria, rationale for sample size (e.g. power calculation), clear plan for sampling and recruitment).

Why 8-12 participants? A rationale for this number is needed.

You provide a clear outline of positive working relationships with key clinicians who will be involved in the recruitment process. You may need to provide further information about what you mean by purposive and convenience sampling for ethics. It was helpful providing supporting details in the Appendices.

Have you considered including demographic information about level of educational qualifications or any additional information about staff training / CPD on bereavement work / bereavement counselling. I also wonder about support structures in work at ▮▮▮▮ e.g. individual or group supervision attended by staff etc?

MEASURES (clearly described measures/interview topic guide, including rationale for choice and discussion of psychometric properties)

The interview questions would benefit from further work and refinement, for example, there does not appear to be any mention of the cold cot or cold bedroom in these questions, yet my understanding is that this is the focus of the novelty of the research. This is a curious omission. Please discuss with your supervisor.

PROCEDURE (clearly describes the conduct of the study and what will happen to participants from the point of approach to exit from the study, methodology is appropriate for the research questions and design)

It is positive that there is support from ▮▮▮▮ for interviews to be carried out in the work setting. On exiting the study, what provisions are there on the day for staff? Have you considered whether you will ask staff not to discuss the interview with other members of the staff team, particularly those who have not yet participated? If not, what implications could these discussions have on the findings?

ETHICAL CONSIDERATIONS (discusses major issues and deals with any potential problems, discusses plans for seeking ethical approval)

These appear to have been considered appropriately.

Please read guidelines on length of time to store UEA thesis research data and amend consent forms accordingly.

ANALYSIS (sets out a clear plan which is compatible with the questions and design)

An alternative to a Trainee on maternity leave may need to be considered for reliability and validity checks within the timeline proposed.

Braun and Clarke methodology for template analysis is appropriate and although limited detail given appropriate references are provided. I was interested to read about your position taken. The style and content of your writing in the introduction suggests that you may hold a number of assumptions before embarking on your research. You may benefit from exploring and discussing these in supervision.

STUDY MATERIALS/APPENDICES (provide documentation relevant to the study, including Participant Information Sheets and Consent Forms, copies of measures where relevant, thesis budget and timeline for study completion)

Please check the order of ethical approval and completion of the focus group and pilot interviews in the timeline and discuss with supervisors.

You may want to consider the explanation of 'confidentially' in the Staff Information Sheet. In qualitative research, authors will often use anonymised extracts and quotes from interviews to illustrate themes - this is not clear from the I.S. and if you state that all information is confidential to a staff group they may be surprised to find quotes in a final write up.

You need to add information about complaints procedure to I.S.

What happens if a participant states Yes on Consent Form to wanting to validate transcript then does not return it?

Consent to Contact Form lacks title.

Where is the demographic form?

It is unclear how you will liaise with charities.

PRESENTATION (extent of typographical, spelling and grammatical errors, quality of referencing**)**

Overall, well presented.

Please read APA guidance on provision of DOIs and URLs in the reference list.

OVERALL STRENGTHS & WEAKNESSES OF THE THESIS PROPOSAL (outline these in detail).

This is an important study, identifying a gap in the psychological literature with clear clinical relevance. The thesis proposal and ultimate thesis portfolio write up will require further work in order to place this research within a solid theoretical grounding. Currently the theoretical underpinnings are not explicit. Further work is needed on the research questions / semi-structured interview and on the Appendices before submission to ethics. This study has the potential for wider dissemination at conference and in a journal publication, in addition to being of clinical use locally. You have done well to embark on a research topic in an emotionally challenging and clinically relevant area.

Markers Required Changes if assignment failed (resubmission required)
Any required changes have to be made to the satisfaction of the markers before the script can be passed. A resubmission of an assignment must be accompanied by a cover letter outlining how the marker's points have been addressed.

N/A

Markers Recommended Changes for Discussion with Supervisor (resubmission not required)

Fundamentally, this proposal is suitable for a thesis project, with a clearly identified gap in the literature. It is realistic and has good support from the clinicians and supervisors involved. Please discuss the detailed feedback provided above with your supervisor and address these points before submission to ethics.

Appendix E -

Faculty of Medicine and Health Sciences Research Ethics Committee

UEA
University of East Anglia

Research & Enterprise Services
West Office (Science Building)
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591720
Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Meghan Waugh
MED

10.3.16

Dear Meghan,

Project Title: The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at ▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇
Ref: 20152016-42

The submission of your above proposal has been considered by the Chair of the Faculty Research Ethics Committee and we can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

Mark Wilkinson
Chair FMH Research Ethics Committee

CC Kiki Mastroyannopoulou

Appendix F – Approval letter from hospice Clinical Governance Committee
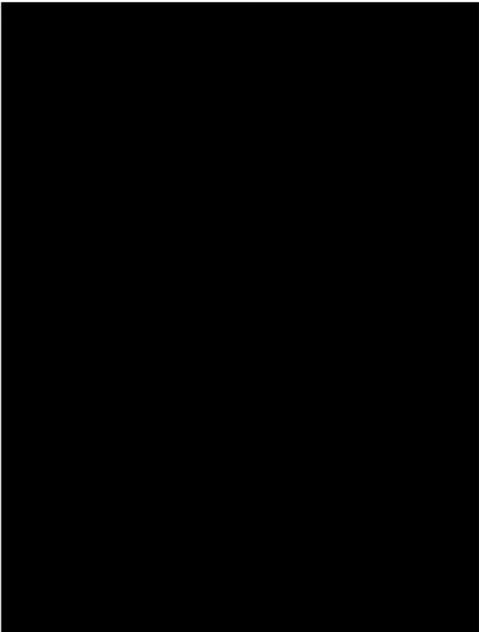
Dear Meghan,

Re: The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at ████████████████████

The Clinical Governance Committee has reviewed the proposal, and approves ████ participation in this research.

If there are any changes made to the proposal the CGC will need to be notified.

We wish you well with your research and look forward to seeing the outcome in due course.

Yours sincerely,
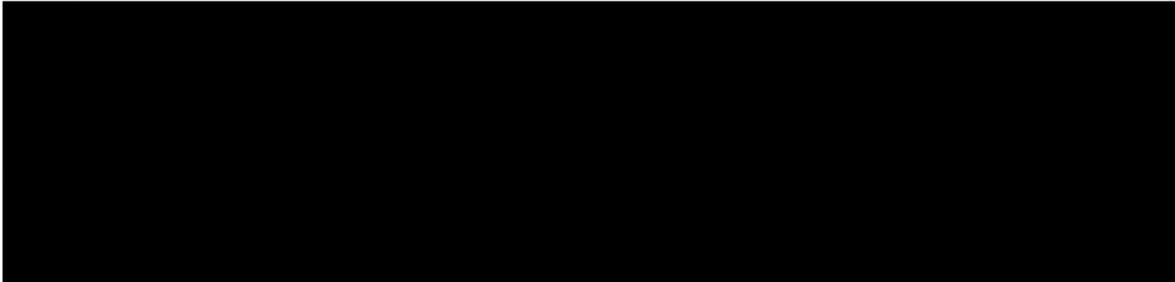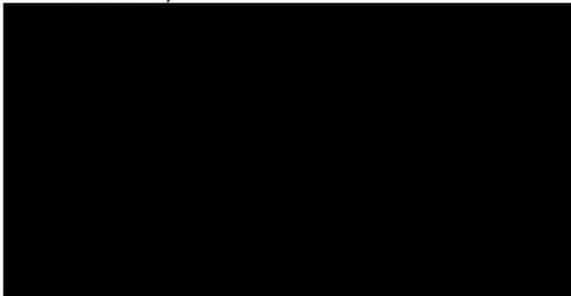
Appendix G – Amendment Approval from FMH Research Ethics Committee

Faculty of Medicine and Health Sciences Research Ethics Committee

UEA
University of East Anglia

Research & Enterprise Services
West Office (Science Building)
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Meghan Waugh
MED

Telephone: +44 (0) 1603 591720
Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

26.4.16

Dear Meghan,

Project Title: The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at ▮▮▮▮▮▮▮▮▮▮▮▮▮▮
**Ref: 20152016-42**

Thank you for your e-mail dated (14.4.16) notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

Mark Wilkinson
Chair FMH Research Ethics Committee

CC Kiki Mastroyannopoulou

Appendix H – Participant Information Sheet

The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at XXXX.

My name is Meghan Waugh and I am a Trainee Clinical Psychologist at the University of East Anglia. My research supervisors are Kiki Mastroyannopoulou (Clinical Lecturer) and Dr Paul Fisher (Clinical Lecturer), who are members of staff on the Clinical Psychology Doctorate Programme at UEA. I am writing to invite you to take part in a research project about staff experiences of using the 'cold' facilities at XXXX. Before you decide if you want to take part, it is important for you for to understand why the research is being done and what it would involve for you.

What is the purpose of the project?

This study will seek to interview staff members who have a significant role in caring for an infant who has passed away and their families, who were referred to XXXX through the Neonatal End Care Pathway at the XXXXXX. Interviews will be seeking to understand the sense you make of caring for an infant after death and supporting a recently bereaved family, and your experiences of caring for families who you may not have a long pre-existing relationship with. We are also interested in finding out about the emotional impact of this work, and the needs of staff working with these families. A good deal of research has been done looking at staff experiences in palliative care and general staff support needs in hospices, but to date no research studies have explored the experiences of staff caring for infants and their families post-mortem. We're hoping that this study helps to fill a gap in the existing literature.

Why have I been invited to participate?

You have been given this Information Sheet as you have worked at XXXX for at least 1 year and have experienced supporting families through the recent loss of an infant. To take part, you will need to be able to understand and sign the consent form provided. I am looking to recruit 6-10 participants and aim to interview people from a range of job roles within XXXX to capture the full experience of this service. We would anticipate that everyone who meets criteria and voices an interest will be interviewed, however in the event that certain job roles are over represented not everyone will be asked to participate.

Your participation is entirely voluntary, and if you decide not to take part in this study, your employment will not be effected.

What will happen if I consent to take part?

If you decide to take part in this project, we will agree a convenient time to undertake an interview, which will take place at XXXX during your working day. I will gather demographic information from you including your gender, age, ethnicity, job role, length of time in post and length of time in a caring profession. I will then ask you questions related to your experiences of using the 'cold' facilities in supporting families. Each interview will last between 45-60 minutes and will be recorded using a Dictaphone. Once we have finished the interview, I will transfer the recording to an encrypted memory stick (via a laptop) in front of you and will then delete it from the Dictaphone. If you would be interested, I will send you a copy of the interview after it has been transcribed for you to read and confirm whether or not it is an accurate representation of your words.

When the interviews have finished, I will be conducting a thematic analysis in order to see which themes emerge from all of the participants. Again, if you'd be interested, I can send you the initial analysis of the interviews I have undertaken for you to decide whether or not you agree with the overall themes.

What will happen if I become distressed?

If you do become distressed in any way whilst being interviewed, I will stop the interview. I would inform my supervisors about the situation without providing any of your identifiable information to them. You would also be encouraged to use the support available at XXXX and to contact XXXXXX in the first instance. If you feel unable to do so, you can contact my academic supervisor at UEA, Kiki Mastroyannopoulou (Clinical Psychologist), to discuss where to access other types of support.

What do I have to do if I would like to take part?

If you are interested in being part of this study, you will need to either contact me or return your Expression of Interest Form to arrange a convenient interview time and to provide your written consent to take part.

Are there any expenses to me to be involved in the study?

No, I will travel to XXXX at a time that would suit your work schedule.

What are the disadvantages and risks of my taking part?

As we will only be discussing the nature of your work which you have been doing for at least 1 year, it is not envisaged that there are any risks to your taking part. We appreciate that you are giving up your time to be interviewed, however, and you will be informed that we can stop or pause the interview at any time you need. Additionally, there is the potential that speaking about the emotional impact of your work could be draining in some way. If this is the case, again, we would stop at any time you wanted and either conclude the interview then or rearrange another time to finish.

What are the possible benefits of taking part?

There will be no direct benefits to you for taking part in this study. However, this project will be running alongside another looking at parents' experiences of using the 'cold' facilities at XXXX, and we are hoping that both of these studies will add to the small evidence base of the usefulness of the cold facilities, and how they are experienced by both service users and staff.

Will information be kept confidentially?

All information will be stored in locked facilities at UEA, and identifiable information would be stored separately from interview transcripts. No identifying information will be included in the write up of this study. All information will be treated as confidential, unless I am concerned for your safety or the safety of others. In this situation I would need to pass this information on to ensure yours or others' safety. You have a right to withdraw from the study up to the point of analysis of the transcripts, as it will not be possible after this point to remove your anonymised information. I will be undertaking the transcription and analysis of your interview, and it is possible that it may also be reviewed by one of my academic supervisors to ensure I have accurately captured the content of the interview.

The final write-up of the study will include quotes from the interviews in order to give examples for the themes identified through the analysis. While these will be anonymised, I appreciate that there is the risk that your words could be recognisable within your staff team. After we have completed the interview, if you would like, you can be sent a transcript of the interview and can request any specific passages not to be included as direct quotes.

All interviews and transcripts will be stored on an encrypted memory stick, and transcripts will be backed-up on University computers on a password-protected file. All transcripts and audio files will be securely destroyed once analysis has taken place or you have withdrawn from the study.

Who has reviewed the study?

This research has been reviewed at by the Faculty of Medicine & Health Sciences Research Ethics Committee at UEA, and has been granted ethical approval. It has also been reviewed by the XXXX Board of Trustees, who consider the ethical implications of all projects related to their staff or service users.

Should you have any questions at all, I would be happy to talk with you about my project further and can be contacted on m.waugh@uea.ac.uk and we can arrange a telephone call if you would like.

If you are uncomfortable with any part of this project or wish to speak to one of my supervisors, they can be contacted on:

01603 593599

K.mastroyannopoulou@uea.ac.uk

P.fisher@uea.ac.uk

If you would like to make a complaint about any part of this study and would like to speak to someone outside of the project team, you can contact Dr Ken Laidlaw (Director of the Doctorate in Clinical Psychology programme).

k.laidlaw@uea.ac.uk

Version 1.3 – 14.04.2016

Appendix I – Consent Form

Consent form

University of East Anglia

The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at XXXX.

Please initial the boxes

1. I confirm that I have read the Information Sheet for the above study.

2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. I understand that my participation is voluntary and I am free to withdraw involvement until data analysis has begun, without giving any reason.

4. I understand that if I withdraw from involvement, my data will be removed from the study data set unless the analysis has already begun.

5. I understand that my interview will be recorded on a dictaphone.

6. I understand that all data collected will remain confidential, and that this will be stored securely and destroyed at the end of the study.

7. I understand that direct quotes from my interview may be used in the final report and I have the right to request specific passages be omitted.

Would you like to receive a copy of the transcript following the interview? Please delete as appropriate:
           YES   NO

Would you like to receive a copy of the initial analysis to validate the findings? Please delete as appropriate:
           YES   NO

Would you like to receive a copy of the final paper? Please delete as appropriate:
           YES   NO

_____   _____   _____

Name of Person   Date   Signature

_____   _____   _____

Name of person taking   Date   Signature
consent

Thank you very much for your help.

Meghan Waugh (Trainee Clinical Psychologist) – m.waugh@uea.ac.uk

Version 1.2 – 26.02.2016

Appendix J – Expression of Interest Form

University of East Anglia

Expression of Interest Form

Please complete this form and return it to me if you wish to find out more about taking part in this study. This form is not a consent form, and you are under no obligation to take part in the study after being contacted. I **will only be able to get in touch with you if you provide me with your contact details.**

Your Details		
Surname (Last Name):	**First Name:**	

Title:
    Mr / Mrs / Miss / Ms / Other _____
	Date of Birth:	**Sex:**
		    Male / Female

Telephone Number:	**Mobile number:**	
Address: **Email Address:**		
If you have a preferred method of contact, please circle one: By Telephone By Post On Your Mobile By Email		

Meghan Waugh
Faculty of Medicine and Health Sciences
Doctoral Programme in Clinical Psychology
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

m.waugh@uea.ac.uk

Appendix K – Confirmation of Accuracy Sheet

University of East Anglia

The experiences of staff who care for infants who have recently died and their bereaved families through use of the 'cold' facilities at XXXX

Please initial the box

1. I confirm that the transcript is an accurate account of the interview

2. The transcript is not an accurate account of the interview

If you believe that the transcript is not an accurate account of the interview, I will contact you to arrange a meeting to discuss your views.

_____   _____   _____

Name of Person   Date   Signature

_____   _____   _____

Name of person taking   Date   Signature

consent

Thank you very much for your help.

Meghan Waugh (Trainee Clinical Psychologist)
m.waugh@uea.ac.uk

Appendix L – Demographic Information Form

Participant Number: _____

Demographic Information	Details
Age of participant	
Gender	
Ethnicity	
Length of time in current post	
Length of time in a caring profession	
Qualifications	
Additional professional development training	

Appendix M – Preliminary Topic Guide

Preliminary Topic Guide (for consultation)

What are the experiences of staff who work at XXXX in supporting families after a posthumous referral to the hospice from the NICU?

- What is it like supporting a family who are newly bereaved? (How does it make you feel?)
- How much of your overall workload is taken up with these families? (What are your thoughts on this?)
- What are your feelings after you finish one of these work days? (Do they differ from how you feel after leaving work on other days)
- What do you think it is that enables you to do this kind of work? (What drew you to this role?)
- How do you feel about the service that you offer these families?

How do staff make sense of working in an environment where an infant's deceased body may be present, when this is not their full-time role within paediatric palliative care?

- What is it like for you to spend time around an infant who has passed away?
- If applicable, what is it like to monitor the state of the infant over the days to weeks you are looking after them? (Does this ever affect you emotionally?)
- Is there anything different for you personally in caring for an infant who had passed away versus providing palliative care for older service users?

What do staff who support families after a recent bereavement through the cold facilities perceive their needs to be?

- Do you have support needs which are specific to working with these families?
- How do you deal with a family's grief? (Does this ever affect you emotionally?)
- If you at times experience distressing emotions working with these families, what do you do with these?
- Is there any impact on your personally from working with these families?
- Do you feel there are any limits to how much time you can spend in this part of your role? (If so, what do you think impacts on this?)
- Does this part of your role affect your overall wellbeing? (If so, how do you address this?)

Appendix N – Interview Schedule

Introduction to the study, explaining the two pathways we're talking about (referrals made through the neonatal end of life pathway at the XXXX, where the baby has either died on the unit or in the hospice after referral/transfer from the NICU), why the study is being done and emphasising that I'm interested in finding out about their internal experiences of this aspect of their work.

1) Thinking about your role within this neonatal pathway, can you tell me about your job?
   (*Prompt:* What is it like for you to look after a family after an infant has died?)

2) Tell me about a particular experience (situation/occurrence/instance) that made a lasting impression on you.
   (*Follow-up/Prompts:* What was it about that experience, how was this different from other experiences, what happened next/what did you do with this?)

3) Tell me about the first time you cared for a family through this pathway
   (*Follow-up/Prompts:* Have things changed? How? Why do you think that might be?)

4) Is there anything different about caring for a baby who's died rather than an older child?
   (*Follow-up:* why, how do you manage this, has this changed over time for you?)

5) How do you feel about the service you offer to families?

   (*Follow-up:* What helps you do your job well? What helps you manage the demands? Both inside yourself and thinking organisationally or externally? Is there anything not currently in place that you think would help you?)

Appendix O – Example Transcript and Codes

<u>Guide:</u>

P02 = participant

R = Researcher

Pauses over 3 seconds are denoted as 'pause' and then the length (pause: 05s). Up to 3 seconds are denoted as ellipses.

Vocal emphasis is denoted in italics

Non-verbal speech notes are made in brackets (i.e. [whispering] [laughs] [gestures]).

Interviewer responses throughout are omitted if incidental and within the participant's responses (i.e. 'mmm', 'yes', 'right', 'okay'), in order to maintain the flow of the transcript. All substantive responses are included as separated entries.

Identifiable information was discussed as it occurred in the interview, and in this transcript all identifiable information about both the interviewee and particular services users has already been removed. An asterisk denotes where identifiable information has been removed and (where possible) more generic terminology has been substituted and is in bold lettering.

Initial codes are denoted in yellow parenthesis brackets. (Example)

P02: Um, it's just what I do (personal characteristics). Um, I've been here a long time (experience); it's just what we do. So, yeah… have I become used to it? Um, do I worry about it, do I take it home? No… No… I think because I know we've got really good policies and procedures in place, it works (organisational structures). It works well. Um, and I think it makes a significant difference to the families (perception of work –makes a difference to families).

R: Absolutely, I think you can tell that from talking to any staff here that the work that you do is just so, so important to the families.

P02: And I think I almost see a difference in the families that use and have their child either at home, or here. In comparison to those who don't. I think there's something very different that happens (sense making).

R: What do you think that is? What's, what's…

P02: I think there's… I don't know. I've often wondered about wanting to do something with that myself (active reflection), because I think there's a piece of work there. I think there's something in this acceptance… um, and making it real (perception of work - enabling acceptance of loss). Automatically, people jump in and you know, you'll hear other relatives say, um 'oooh, it's not very healthy is it, seeing them every day, ooh no, why would you do that, why would you want to do that. Ooh it's not very healthy it can't be very good for you' (outside perspectives). But I

actually think it's the opposite, I think it can be really healthy. Because it promotes that acceptance, it promotes the saying goodbye, the natural detaching and understanding and stepping back. (perception of work – important to family) Um, yeah – it's really hard to put into words what I see happens (active sense making). Um, but families talk very differently when you hear them talk, like in our bereavement group, when you hear someone talk who had this experience and someone talk who didn't, there is something different (perception of work – important to family).

R: Okay, that's interesting. Can you think about any, any particular time when you've cared for a family after an infant's died that's really stuck with you? I know you mention you've been here a really long time, but is there one…?

P02: Um. Yeah? Yeah, I mean… obviously they're all different. Some stick with you for… different periods of time, depending on your relationship, um, with that family (relationship with family). Because quite often, if it's not *my* family as such, it's one of my colleagues families and then I will still go and check on them, but probably the impact on me will be much less (length of relationship affects the impact). Because I can be much more detached, I don't… ya know, I haven't spent that quantity of time with mum and dad (length of time with family), um so if I'm just looking out for them for my colleague, it is a different experience. But yeah… lots of situations where mums have been, and dads have been able… I've had one family where their little girl… yeah, she died here and um, ya know, mum would just read her a bedtime story every night. And was able to take her out, she wanted desperately to take her into the light room and so we just facilitated that happening in… (enabling special experiences) it was something that she just wanted to do once more. Um and I've had families where they've just wanted to take them for a walk and it's just doing those really special things that… (pause: 05s) (doing things once more) (perception of work – important to family)

R: That stuck with you a bit?

P02: Yeah, yeah I think they're things you remember because you know that you've made them happen where people automatically sometimes think… I think people think that when they're dead, you can't continue to make memories. And you can't continue to bond. (outside perspectives) Where I've seen many mums come from NICU and bond with their dead baby (perception of work – important to family). People are quite horrified when you say that, that you can actually still bond with your dead baby and that you can still have skin to skin. They're quite horrified... (outside perspectives) But we, I certainly promote it.

Appendix P – Example of Initial Coding Groups

Example of Initial Coding Groups

Making Sense of Experiences

- Reflecting on how outsiders see things (P01 – 275, 429-430, P02 – 48-50, 81, 82,83, 178-179 , P03 – 250-251, 343, 480-481, P04 – 348, P05 – 128, 700, P07 – 437, 462, 473-474, 475, 487, 492
    o Cold, heartless, emotionless – who am I if I can do this job?
    o As a society we avoid death P07 492)
- Awareness of responses (P01 – 335, P02 – 148, 160, 161, 501, P03 – 125,126, 169, 238-239, 320, 493, P04 – 132, 165-166, P05 – 100, 195, 430, 432, 606, 617, P06 – 114, 220, 345-346, 372, P07 – 152, 207-209
- Active sense making (P01 – 254-255, 277-278, 335, 354, 364, P02 – 105, 123-124, 125-127, P03 – 133-134, 140-141, 171-172, 250-251, 407-408, P04 – 128, 233, 442, P05 – 290, 295, 669, P06 – 105, 106-107, 109-110, 206-207, 403-404, 408-416, 432, P07 – 160, 232-233, 528-529, 620,
- Not finding the words (P01 – 277-278, 362-363, P04 – 126, P05 – 680-682, P06 – 182, 404
- Comparison to real situations (looked real/normal situation) (P01 – 193-194, 196-197, 206-210, P03 – 150-151, 171-172, P06 - 76
- Questioning of self (P01: 386, 393, P02 – 106-107, 112, 188, 288, 289-290, 627, P03 – 267, 539-541, P04 – 347, 350-351, 364, P05 – 171, P06 – 116, 117-118, P07 – 207-209, 232-233
    o What does this say about me?
- Adjustment (P02 – 34, P03 – 303-304, P04 – 129, P06 – 105, 115, 127
- Having a word with myself (P02 – 199-201, P03 – 498, P04 – 281, P05 – 31, 405, 534, 537
- Checking out what's driving own responses (P02 – 503-504, P03 – 407-408, P04 – 177, P05 – 118, 145, 224, 238, 602-603, P06 – 125, 395-396

Emotionally affected

- Hard (P01 – 266-268, P04 – 48, 52, 306, P07 – 56-66
- Affecting/Moved (P03 – 166, P05 – 40, P06 – 196-197, 423
- Some things difficult to see (P01 – 309, 310, 311, 314-315, P03 – 282, 365, 403, P04 – 324, 510-511, P06 – 128,
- Full term babies harder (P01 – 312-313, 368, P02 – 497-500, P03 – 290-297, P04 – 126-128, P06 – 71, 75
- Emotional stories (P01 – 312-313, P02 – 142, 147, 514, P03 – 148-149
- Thinking of own family (P01 – 284, P02 – 182-183, 185, P05 – 146, 521 ,
- Comparison to children/ages (P02 – 180-181, 187, P05 – 147, P06 – 106-107, P07 -243-244 248 268-269, 270
- Relate to own situation (P02 – 102,103; P05 – 145, P06 – 361, 365-367, P07 - 202
- Personal stressors make it challenging (P01 – 289, P03 – 133-134, P05 – 501, P06 – 342-343
        Personal experience helps P07 – 151
- Can't share it outside of work (P01 – 318, 319, 320-321, P04 – 279, 281, P06 – 276, P07 – 413, 437, 448, 453-454
- Loss of hope/What ifs (P02 – 498-500, 514, P03 – 305-307, 312, P04 – 160, 161, P05 – 366, P06 – 98, P07 - 527
- Did I do something wrong? (P04 – 294, 389, P05 – 169-170, P07 - 625
- Not enough time to process (P04 – 306, P05 – 191, 194, 264 P07 - 349
- Too many all at once – P01 – 205, P04 – 295, P05 – 243
- Harder at beginning of the role – P06 – 71,89 P05 – 100, 410
- Burden of taking on other colleagues' pain: P06 – 234-235

Appendix Q – Reflections on Theme Review

Reflections:

- Really wanting to do the data set justice; especially the emotional stories. Stories that touched me to hear, transcribe and code; I want to find a way to make that in. It feels important, but I don't totally know why

- Feel that the authenticity of the data is lost from separating into what makes the work challenging; this is my assumption and interpretation rather than what participants were bringing to me in their words. I was asking for what stuck with them, what was different, what made an impact and had decided that these were what I would call 'challenging'; but thinking back, none of the participants talked to me about an overall sense that their work was challenging. There were challenges, and things that meant they had to use various strategies to cope, but an overall sense was of the work being positive and important to them.

- Challenging feels like an injustice. What do I mean? What were they telling me? They were saying 'I get on, I do my job, I love my job, it is what it is' and were telling me what works well; what supports them. They were showing me characteristics and mechanisms of reflection that helped them actively make sense of situations that others might see as challenging. They could see how outsiders saw the work, and reflect on that, but that wasn't how they saw it. In a way, me seeing it as challenging is what they're saying about others' reflections not really being what it's like.

- Changing the overall theme to being able challenges: because challenges aren't inherently negative; running a marathon is a challenge, finishing a doctorate is a challenge. They're not negative, but participants are telling me the bits about the job that require them to do something different, the bits that require an out of ordinary response.

- This helps relate more easily to the other primary theme of 'what enables staff to overcome challenges'; this reflects the sense of empowerment and mastery that came through the interviews. These were staff who could acknowledge that some things were difficult, some bits were hard at times, but they had skills and resources that meant the overall sense was that work was positive, fulfilling and rewarding.

- In writing the results section of the empirical paper, I feel more strongly that I'm losing the depth of the data. I'm confident that the themes and subthemes encapsulate the overall sense of the data corpus, but some of the heart is gone. I feel particularly strongly about a couple of stories within the data that I had to exclude because of both space and concerns about confidentiality; but they feel incredibly moving and powerful. I feel like they don't necessarily fit into the themes, but they really made me understand how some of these experiences might feel. Particularly these two:

"P06: Um [pause: 04s]. No, I don't, I think sometimes I might be caught unaware by a parent's response if they do something that I hadn't seen before. I might process that a bit differently at the beginning. There was one mum who, um, stroked her baby from head to toe and then kissed her baby all over and I hadn't seen that before. So for me I was just processing that in the moment. It almost, when I was in the room, she had asked me to go in the room with her, and she was getting her baby ready, and dressing her baby. Um, I felt like I was intruding, and that, I hadn't felt that in my role before. I felt like I was watching, and I appreciate the mother

needed me there, but it felt a really intimate thing that the mother was doing, so I, that moment I just stayed quiet. But I did feel almost like I was looking at, I was, it felt for me that it was a bit intrusive. But obviously for the mother it didn't. But it just seemed like it was a beautiful moment for them, but I was there in the room.

R: Wow. That's really… quite fascinating too because I'd think… you'd, you'd be around a lot of intimate moments as well but there's something different…

P06: Yes, and I think because she worked her way down her whole body and then back up, and just caressing and stroking and it was like a, a goodbye but also a tactile 'I'm going to touch every part of you'. And yes they do, they, parents will quite often stroke the hair, wash the hair, clean them, bathe them, cuddle them… um, and, all sorts of intimacy. But it was just… it was just, it felt really intense in the moment. It was like, 'I know I'm never going to be able to kiss you as many times as I'd like so I'm going to do it all at once'. It was… it kind of, she followed a system. She went right, ya know, from the head right back down and then right back up, and it felt like she couldn't miss a spot. It felt really… and I hadn't seen it before, other staff may have, I don't know. And I haven't seen it since. So they're the little bits that are unaware of the something different."

And:

"R: And so you mentioned working through it when you've had that sort of experience – um, do you, I think I've possibly asked this before, but I'm going to do it again – do you, do you know what – can you explain that process? Something has caught you off guard, and it's there, and what's next to process it?

P06: I think I try and focus on why that was different. What did I experience differently in the moment. And why was it. Does it have a link with something personal for me, or was it just that that was something so, um, moving, and it might have just been that it was very moving. Or it might have been something that was quite different. Quite often the children and the babies will go from here via the funeral directors onto the funeral. That's quite common, I've done that lots of time. But I had one instance where the parents said 'will you watch the child go down the drive just off the car park' because the child was going to them, and then they were going to funeral. So their baby was leaving unattended from here just with the funeral directors. So would I see them just off the car park. And that's nothing unusual, they just wanted to see them gone, just to know that we were handing that care over. And the funeral director, I'd seen him do it a hundred times, took his hat off and walked in front of the coffin. They do a slow walk up the drive. And um, I think I'd have just done it on my own, the mum phoned me at the last minute, I was in the car park on my own, and I was in floods of tears. And I've done that so many times, so it was like 'what was different, what was different about this that made that so emotional for me?' – so then I would go away, and I might share that with someone, or I might keep it to myself

and process it first. It just depends on what. So there was something in that situation that triggered that response for me.

R: And you worked out what it was?

P06: It was the balloon. The funeral directors had been asked to release a balloon. And I think, when the balloon went off, and I'm always quite moved by how the funeral directors still do that walk even though nobody's there to witness it from the family. They do it quite a way up the drive, and it's very slow and meaningful, and I think I just thought – 'that baby is now going alone until it meets its mum' and I just pictured it so alone from being here, and then doing that bit on their own. And when that balloon went up, I think that just, the balloon was on its own and I think there was just an association and a, a trigger.

R: It sounds really powerful actually.

P06: And coming back I was able to pick up that it was that aloneness that moved me. That that baby was so well cared for here, so well cared for by its family when they came in, but they just couldn't get in to do that bit of the journey.

R: It sounds almost beautifully respectful.

P06: Yes, that everyone was still caring. The funeral directors just were so respectful, despite the fact that the parents weren't there to see it. And they released the balloon like she'd asked, and ya know, it just felt that everyone was so respectful of this tiny little baby.