Edinburgh Napier University

"It's not our grief to have…?"

The lived experiences of professional grief that palliative care nurses experience whilst delivering end of life care in acute hospital settings.

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of
Doctor of Philosophy

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Declaration

I hereby declare that the work presented in this thesis has been conducted by myself.

This thesis has not been presented for any other academic award.

Geraldine Finnan

Acknowledgements

Dedication

I would like to dedicate this thesis to my late mother and father, Nora and Tim, who inspired me to be all that I could. Their kindness, compassion and wisdom shone through in all that they did and instilled in me a respect for love, life and friendship. My mother and father died some time apart throughout completing the thesis and the loss I experienced each time necessitated a break in my research but the decision to continue was borne from a much deeper and personal understanding of the nature of grief and loss. My mother died in an acute ward in a busy urban hospital and my father was cared for at home with the help of a Hospice team. The care afforded them was equally caring and compassionate but the subtle difference of truly being with and alongside the dying and bereaved was much more evident with my Fathers care and I hope this work goes some way to illuminating the need to support nurses in acute settings in the delivery of end of life care and support of the bereaved.

I know they would have been extremely proud of the completion of this thesis and that makes me smile. Thanks Mum and Dad.

Abstract

Background

The population in Scotland is ageing with a projected increase of 75% in the over 75's by 2031. Currently over 55,000 people die in Scotland each year. This figure however is increasing and over half a million people will receive end of life care and die in acute settings in the next twenty years. The palliative and end of life care (PEOLC) needs of the population will increase and will be delivered more frequently in acute settings. The personal experiences of the nurses delivering PEOLC in a busy acute environment therefore require to be reflected upon, understood and acknowledged.

Nurses experience grief for their patients, but do so in a very different manner to that experienced by the patient's family. The nurse often finds them self in conflicting roles as they feel they need to remain strong and offer support on one hand whilst managing their own emotions and acknowledging their loss on the other. Managing their experience of professional grief following the death of a patient with whom they may have formed a connection can be very difficult.

This purpose of this study is to understand the experiences of palliative care nurses delivering PEOLC in an acute settings and how they make meaning following loss and death of patients.

Methods

This research was underpinned by a reflective approach and engagement with the participants using an Interpretive Phenomenological Analysis (IPA) methodology. IPA has become a credible methodology for studying consciousness generally and in nursing in particular. Analysis of the meanings being lived by participants from a psychological perspective can be illuminating and revealing in nature.

Seven nurses were recruited using purposive sampling from a palliative care ward based in an acute hospital setting. The researcher was able to cultivate a deep level of trust and collaboration through having knowledge and

experience of the palliative care nursing role within an acute hospital setting and an understanding of the roles and responsibilities within the team.

Data were collected through seven semi structured interviews which were audio recorded then transcribed, field notes were recorded prior to the interviews and reflections were audio recorded post interview. The three data sets were drawn together to triangulate findings.

The analysis which ensued combined the researcher and participants reflections, double hermeneutic approach.

Findings

Following analysis of the findings, four main or superordinate themes were revealed. These were the importance of being, the altruistic self, separating the personal and the professional self and death anxiety and transference.

The nurses instinctively knew when being with the dying patient was not only needed but also invited. The nurses inherent values and altruistic tenets ensured they delivered care to the highest standard they could, and believed that this contributed towards a good death for the patient. They felt personally responsible for ensuring a good death was achieved.

The nurses did experience a form of professional grief and feelings of loss for their patients following their death. The process of experiencing grief, although often short lived, caused concern to the nurses. They perceived it as not being professional to show outward signs of grief as their primary role was to support the dying and bereaved. Death anxiety and transference were consequences of delivering palliative and end of life care in this setting. Although nurses sought to address these experiences through processes of reflection and team support activities, evidence of distress and grief persisted.

Conclusion

Nurses are sentient thinking beings whose lived experiences and feelings affect their thoughts and emotions. This in turn impacts not only on their personal life but also their professional identity and perceptions of good quality care. The caring processes they enact shapes and informs their

understanding of the world and their experiences therein. The findings of this study point towards a need to understand and acknowledge that nurses can experience professional grief for their patients and it is necessary therefore to consider effective supportive mechanisms such as reflection and formal clinical supervision for nurses delivering PEOLC in acute settings. This could support wellbeing, where nurses care for themselves and each other whilst delivering end of life care.

Following identification of the findings an illustration depicting a visual representation of the process of professional grief experienced by nurses delivering PEOLC in acute settings is presented. Four stages of being were identified within the process. These were feeling prepared, experiencing loss, making meaning and finally letting go and moving on.

The conclusions and illustration depicting a visual representation of the process of professional grief have been grounded in the findings from this study and therefore offers an original contribution to the knowledge and understanding of the experiences of palliative care nurses delivering PEOLC in acute settings.

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Introduction

1.1 Introduction

The purpose of this study was to explore and gain an understanding of the lived experience of the palliative care nurse, delivering care in an acute setting, after the death of their patient. The relationship the nurse had with the patient, the family and their own team was explored to understand their lived experience of grief or loss felt following the death of the patient. A qualitative approach, informed by interpretative phenomenological analysis (IPA), explored the grief experience of nurses who cared for dying patients. This is a credible methodology used for this type of study. The study was particularly concerned with how the death of patients impacted on their own experiences of grief and loss both personally and professionally. This chapter begins with the statement of aims and objectives and continues with an overview of palliative care which helps situate the research topic within contemporary practice. In addition the structure of the thesis is described and the researchers perspective, thoughts and feelings stated.

1.2 Research Question and objectives

The overarching aim guiding the current research is to explore and understand the lived experience of professional grief that palliative care nurses in an acute setting experience whilst delivering end of life care and care after death. Three guiding research questions were developed :-

1.   What are the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying ?

2.   What is the palliative care nurse's response to the loss of a patient when working in acute settings?

3.   What is the meaning of loss and death experienced by palliative care nurses working in acute settings after the death of a patient ?

1.3. Overview of Palliative Care

Fifty million people die globally each year often without suitable pain or symptom control (Paice et al., 2008). Palliative care, a multidisciplinary method of care, was developed in order to deliver care which supports the unique needs of a dying patient and their family. Its goals are to bring together many disciplines to provide the complex care needs of the dying patient and their families. Defining the terms palliative and end of life care is essential so as to understand the context in which they are practiced and the implications for the practicing nurse.

Palliative care is a method of care used when a cure is not possible. It is a proactive and multidisciplinary approach. The goal is to control distressing symptoms such as pain and nausea and encompasses a holistic approach which meets the practical, social, functional, physical, emotional and spiritual needs of patients who face progressive illness and carers who eventually face bereavement (Paice et al., 2008). It was initially developed to provide for the care needs of cancer patients but now includes all conditions and illness trajectories such as dementia, motor neurone disease and multiple sclerosis. The World Health Organisation (WHO) first defined palliative care and redefined the description again in (WHO. 2012). They described it as an approach to care that not only improves the quality of life for patients but also for their families facing problems which are associated with a life limiting illness.

The aim is to provide relief from pain and distressing symptoms, to affirm life and normalise the dying process. It also integrates the psychological and spiritual aspects of care offering support systems to allow the patient to live as well as possible until death (WHO. 2012). Essential components of palliative care include allowing the patient choice where possible, involvement of the family and good communication (Fallon and Hanks. 2006). End of life care is a component of palliative care and concerns patients who are deemed to have a life expectancy of less than one year.

The development of palliative and end of life care gathered pace in 1967 following the establishment of the first hospice in the UK by Cicely Saunders (Kinghorn & Gamlin. 2001). It was not until 1985 however that the

Association of Palliative Medicine for Great Britain was formed and palliative care started to gain significance as a field of medicine in its own right. The philosophy of care for palliative and end of life care differs from the accepted medical models of care and this area together with a focus on the attributes of the palliative care nurse is explored further throughout the study.

1.4. Position of the Researcher

My professional background is that of a palliative care nurse and quality improvement facilitator for palliative and end of life care. Prior to training as a nurse as a second career. I was a Project Manager for a large retail organisation. The skills and attributes of a project manager influenced my training and development as a nurse and led to the desire to understand the processes and understand how palliative care nurses made meaning whilst providing end of life care to dying patients and their families. The skills learnt throughout my career as a project manager were applied to gathering, collating and framing data for this study.

One significant event during my nurse training influenced my choice of palliative care nursing and shaped my career to date. I have used a pseudonym for the patient to ensure patient anonymity (RCN. 2018).

Mr Owen was near to the end of his life and on, what was termed at the time as "the palliative care pathway" He was very frightened. Mr Owen became very anxious and restless and constantly pressed the call bell. On one occasion I answered the bell and asked him what was wrong and he replied that he did not know. I then asked if he was in pain and he replied "*well not physical pain*". I did not know how to react to this statement as I felt I did not have the necessary skills to offer support. I did however know that this patient needed a presence and somebody to talk to. I pulled up a chair and we proceeded to talk about his fear and illness. I tried to reassure him and reminded him that his wife and family would be in at visiting time and assured him that I would call in to see him every twenty minutes or so until the end of my shift. At the end of my shift which was a Friday night I went in to say good bye, saying I would see him Monday morning to which he replied that he would not be here. I found it difficult to find a suitable reply

but tried to reassure him one more time. When I attended my shift on Monday I was told that he had passed away over the weekend with his family at his bed side.

Identification of thoughts and feelings

My initial thoughts and feelings were that of sadness and regret. I had thought about Mr Owen throughout the weekend and had decided that I would ensure that I spent time with him once I returned to the ward on Monday morning. I had been thinking about the situation and his obvious desire to speak to somebody about his fears. I decided to speak to my mentor about how to offer help and support to Mr Owen. I was happy that he had his family round him when he died but felt I could have offered more support during his period of anxiety. I also felt frustrated that I did not know the correct way to respond as I had never been in the situation before and felt unqualified to offer anything meaningful. I went on to pursue a career in palliative care and endeavoured to equip myself with the necessary skills to help patients in similar situations in the future.

The desire to undertake this PhD was the result of a conversation, again around death and dying during a night shift on a palliative care ward. The conversation turned to nurses dealing with feelings of grief following the death of one of their patients and how the death or the grieving family members made the nurse feel. An experienced palliative care nurse who was part of the conversation stated that nurses should not allow themselves to become too involved on an emotional level with the patient or the family and stated

> *" It's not our grief to have"*

I found this statement intriguing and wanted to explore the meaning behind it further.

Early in the study I established that a qualitative approach would best suit the aims and objectives of the study. Interpretative phenomenological analysis was deemed the most appropriate method, see chapter 5 for further analysis of this decision. My position as a researcher in a palliative care role should be viewed as integral to the process. I previously worked alongside the nurses in the study and therefore had first-hand experience of

their daily work. I viewed myself as an insider with credibility to fully understand the explicit and implicit description and meaning making of caring for patients approaching death.

1.5. Structure of the thesis

This thesis presents the results of an interpretative phenomenological analysis of the lived experiences of professional grief that palliative care nurses experience whilst delivering end of life care and care after death to patients in an acute setting. The thesis is divided into ten chapters. Following the introduction chapter the subsequent chapters are outlined below.

Chapter two presents the background to palliative and end of life care development and how the discipline started to gain significance as a field of medicine in its own right. In order to fully understand the demands of the palliative care nurse in an acute setting in Scotland, policy development must be understood together with the impact this has on service design. Due to the changing care needs of the population of Scotland which require palliative and end of life care, practice has and must change to meet those needs. It is critical to the context and understanding of this thesis that the background to palliative and end of life care is presented.

Chapter three presents the findings from the literature review undertaken through the framework of a scoping review to explore palliative care nurses delivering end of life care in an acute setting and their meaning making of loss and grief. The concept of a good death from a nurses context is examined. The significance of relationships at end of life are identified together with spirituality and compassion. The importance of communication and being supported within a team are also discussed. Finally the characteristics of a palliative care nurse are identified, which support the ability of the nurse as a person and a professional to care for the dying and deceased.

Chapter four examines the seminal work around grief theory and frames the discussion for professional grief which follows. Drawing on the findings from the previous two chapters, chapter two and three, this chapter concludes

with a rational for undertaking the study based on current gaps in research and literature.

Chapter five describes the methodology exploring a range of qualitative methods leading to the case for interpretative phenomenological analysis. This case is illustrated using a Strengths, Weaknesses, Opportunities and Threats (S.W.O.T.) analysis and a matrix analysis.

Chapter six discusses in detail the research design and methods.

Chapter seven presents the findings as superordinate themes with extracts to illustrate the main themes. These are the importance of being, the altruistic self, separating the personal and the professional self and death anxiety and transference.

Chapter eight presents the discussion around the findings and suggests the culmination of the discussion should be presented as a gestalt.

Chapter nine presents the gestalt and conclusion and describes the development of a proposed visual representation of grief for palliative care nurses delivering end of life care in acute settings. A further presentation of stages of "making meaning" the nurse experiences when delivering end of life care and care after death was developed and is presented.

Finally chapter ten provides a summary and recommendations for practice and further research. It also includes reflections on the study and limitations of the study.

Chapter 2
Background to Palliative Care

2.1 Introduction

In order to fully address the research aims it is important to understand the development of palliative care both nationally and internationally as a foundation to service design for palliative and end of life care delivered in Scotland today. More palliative and end of life care is being delivered by generalist nurses in acute settings and this has an impact on the delivery of care for patients' and an impact on the nurses thoughts and feelings whilst delivering this care.

The policy which has evolved is based on a strategic approach by the worlds health leaders to ensure palliative care is delivered equitably and in a timely way across all patient groups. Policy drives practice and shapes future delivery and ambitions. The UK is a world leader in palliative care delivery and as such is looked upon as a forerunner for innovative approaches which aim to deliver good quality palliative and end of life care for all those who need it. A new approach to care delivery is evolving as the teams strive to meet the growing demand for palliative and end of life care in today's society. The specialism of palliative and end of life care is no longer confined to specialist units and generalist teams are increasingly finding themselves delivering care to the dying in a number of settings.

In order to understand the development of policy in Scotland, the author reviewed current published policy by the Scottish government and traced the development back through the publications to 1998 when the Scottish Government was formed. International policy was explored and the links and impact on the development of Scottish policy identified. Further hand searches of palliative care related journals and seminal works on palliative and end of life care were undertaken together with a review of conference proceedings.

2.2   Development of palliative care in the UK

Hospice and palliative care can be traced back to "places of welcome" provided by the early Christians to travellers and pilgrims requiring rest and respite (DeSpelder & Strickland. 2005). The words hospice, hospital and hotel are derivatives of the Latin word hospitium, which means "a place that receives guests". In contrast to the Roman model of hospitals that were built on military efficiency to enable speedy turnaround of injured soldiers and gladiators the Christian model of care was aimed at injured travellers and the hopelessly ill and dying. The dying held a place of honour in the eyes of the Christians as they were seen as "spiritual pilgrims "who were close to God (DeSpelder & Strickland. 2005). The origins of the development of institutionalised care for the dying starts with the development of the first hospices appearing in the nineteen century. In 1842 Dames de Calaire was established by Mme Garnier in France and in 1879 and Our Lady's Hospice was opened in Dublin. St Joseph's hospice in East London was opened in 1900. The purpose of the early hospices however were not to solely provide end of life care but were based on the Catholic tradition of providing places of sanctuary for weary travellers first mentioned in medieval times and were underpinned with Christian principles (Kinghorn & Gamlin. 2001).

This separation of caring for the dying from other patients who cure seemed possible could account for the widening of the gap between care of the dying in a hospice setting and those cared for in an acute setting. The delivery and philosophy of care in both areas does not always align. The Christian model of care, providing sanctuary, lays the foundation for our understanding of hospice care today whereas the Roman model of efficiency and turnaround of the injured soldiers equates to a medical model of care.

In nineteenth century Britain, life expectancy was 44 years for men and 47 years for women and most people died at home following a short illness, often cared for by family members and neighbours with the only professional involvement coming from the clergy (De Souza & Pettifer. 2013). The National Health Service was established in 1948 which ensured professional health care was available to all which was free at the point of delivery (De Souza & Pettifer. 2013). This led to a change and by the 1950's most people

died in hospital with the increasing availability of treatments. This shift to a medical model however led to the medical profession seeing the death of a patient as failure. Cancer was seen as the most feared diagnosis due to the physical pain and lack of appropriate painkillers. Morphine was not used due to the belief that it was addictive and too dangerous to use (St Christopher's, 2005).

In 1948 the Marie Curie Memorial Foundation had opened terminal care homes throughout the UK (Marie Curie. 2015). However a significant development in the growth and understanding of palliative care did not develop until 1967 when St.Christopher's Hospice was founded in London by Cicely Saunders (Kingworm & Gamlin. 2001). A new approach to the care of the dying was taken which included a holistic view, caring for the physical, psychological, spiritual and wellbeing of the patient which according to St Christopher's Hospice marked a new beginning for patients at end of life and the field of medicine as a whole (St Christopher's. 2014). This became the prototype model for modern hospice and palliative care units within the UK. Macmillan Cancer Relief had been established 1911 but did not start to contribute towards building hospices until 1969 (Macmillan. 2018).

The hospice movement continued to grow and in the early 1980's palliative care became a speciality. Cicely Saunders is still cited today throughout the palliative care community and many care of the dying practices used today have roots in her research and methods (Kinghorn & Gamlin. 2001).

 In 1985 the Association of Palliative Medicine for Great Britain was formed. In 1991 the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) was formed which brought together many professional organisations under one umbrella in England, Wales and Northern Ireland. The NCHSPCS developed principles which underpin palliative care provision and in 1999 described a palliative care approach as care which was active and covered all aspect of need for patients with a life limiting illness. The approach should also include care of the family. They also proposed that the multidisciplinary team caring for the patient must have undergone recognised specialist training. The Scottish Partnership Agency for Palliative and Cancer Care was formed in Scotland in1991 in line with NCHSPCS and

in 2004 changed its name to the National Council for Palliative Care (NCPC) to accurately reflect the new direction of palliative care which encompassed palliative, end of life and hospice care for all patients in all settings (NCPC. 2015). The development and forming of these bodies went some way to broadening the reach of the philosophy of care attached to palliative and end of life care delivery throughout the acute setting but still the discipline retained a "specialist" description and was viewed as a distinct method of care delivery.

The UK leads the world in the quality of care it provides at death with its hospice network and statutory involvement in palliative and end of life care ranking top amongst 40 countries that were measured as part of a study by the Economist Intelligence Unit. (Economist Intelligence Unit. 2010). The rapid growth and development of palliative care in the UK from the 1960's was not seen in the rest of the world until a decade later when developed countries such as America and Australia started to provide palliative care services as a separate discipline (Wright et al. 2008).

2.3 Development of international palliative care

The WHO has promoted palliative care and pain relief from the 1980's and since then a growing number of national associations collaborated to advance developments in palliative care (Wright et al. 2008).

The International Observatory on End of Life Care (IOELC) published the "world map" report in 2008 categorizing the development of hospice and palliative care throughout the world.(Figure 1) (Wright et al., 2008).

**WPCA Palliative Care Development
All levels (n = 234)**

Level of Palliative care Development (PCD)
- Level 1. Not known activity
- Level 2. Capacity building
- Level 3a. Isolated provision
- Level 3b. Generalized provision
- Level 4a Preliminary integration
- Level 4b Advanced integration
- Data not available

The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the WPCA concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

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Figure 1 levels of palliative care across the world (Wright et al., 2008)

A review of the world wide picture highlighted that America and Australia demonstrated development in palliative care earlier than most other countries globally with the exception of the UK and they are among the countries in group four where hospice-palliative care services are reaching a measure of integration with mainstream service providers. Integration with main stream service providers is presented as a measure of improved quality of care and could be viewed as widening the approach and philosophy of care into acute settings.

The Quality of Death Report was commissioned by the Lien Foundation and conducted by the Economist Intelligence Unit which explored existing research on the topic of palliative care and a good death (Economist Intelligence Unit. 2010). The report combined interviews with experts in the field and applied a ranking system to devise a "Quality of Death" index based on the provision of end-of-life care.

This report also suggested that the UK is a leader in palliative and end-of-life care and that many nations including well developed ones must work to

catch up. Perceptions of death can result in cultural taboos and death and dying are stigmatised in some cultures. The report suggests that policy recognition and support at a high level is crucial. (Economist Intelligence Unit. 2010) consistently citing training, irrespective of country as necessary to equip the caregivers with the capacity to deliver a high standard of care which in turn will allow those patients who wish to die at home the opportunity to do so.

The Quality of Death report concludes that providers of palliative care and governments are in danger of not being able to meet the growing demand for palliative and end-of-life care as the requirement across the globe for this type of care is increasing at a faster pace than can be delivered. They go on to suggest that whilst there is a call to enshrine end-of-life and palliative care in national and international policy as a human right there is a danger it will only exist on paper (Economist Intelligence Unit. 2010).

The World Health Assembly (WHA) is the supreme decision making body of WHO. The assembly in 2014 focused on palliative care and member states were called upon to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care (WHO. 2014). This call to improve palliative care became the driver behind Scotland developing new policies and procedures around their delivery of palliative care.

The UK are the leaders in the delivery of palliative care following evidence gathered whilst mapping levels of palliative care development which was presented in the Global Atlas of Palliative care Report (Wright et al. 2008). The UK still remains within the group of countries where hospice – palliative care services are at a stage of advanced integration into mainstream service provision. Scotland as part of the UK, worked towards developing their delivery of palliative care services to improve the quality of care through the integration into main stream health care services. This would result in more nurses delivering end of life care in acute settings.

In response to World Health Assembly initiative to improve access to palliative care, the Scottish government together with a number of palliative care organisations across Scotland have produced a Strategic Framework

for the delivery of palliative and end of life care (Scottish Government.2015). Prior to this document a number of policy documents detailing the aims and approach of care delivery were produced, however the focus was not usually on palliative care but chronic or life limiting conditions with palliative care made reference to within the document. It was not until 2008 that Living and Dying Well : a national action plan for palliative care in Scotland a key policy document relating solely to palliative and end of life care was published (Scottish Government. 2008).

2.4   Developments in palliative care policy in Scotland

2.4.1 Early policy documents

Following the formation of the Scottish parliament in 1998 there have been a series of documents produced by the Scottish Executive detailing policy statements for the delivery of palliative and end of life care in Scotland. Most of the documents were concerned with particular disease trajectories or care pathways and only mentioned palliative care as a small component of care. It was not until 2008 when The Living and Dying Well report was published that palliative care received the recognition and attention to detail that was required to shape further practice (Scottish Government. 2008).

As the Quality of Death Report suggested, policy recognition and support at a high level is crucial to quality of care delivery and therefore it is important to include policy documents in the literature review as policy shapes practice and the author feels this imparts relevance to the study (Economist Intelligence Unit. 2010). Further description of the content and development of the documents can be found in appendix 1.

2.4.2 The living and dying well report

The Living and Dying Well report was a result of an extensive process of collaboration across Scotland and was also the first national action plan for palliative care delivery (Scottish Government. 2008). The aim of the Living and Dying Well action plan was to ensure that good palliative and end of life care was available for everyone who required it throughout Scotland and that palliative care became a routine part of care delivery. Previously

Hospice care was synonymous with palliative and in particular end of life care and this policy required a shift in focus for the acute setting. There were five aims of the living and dying well report with the overall aim to facilitate quality improvement within all NHS Boards, equipping them to plan and develop services which would deliver good palliative care across all care settings in Scotland. (Scottish Government. 2008).

The report also provided a platform to launch the recommendations of the Scottish Partnership for Palliative Care report titled *Palliative and end of life care in Scotland: the case for a cohesive approach* (Scottish Partnership for Palliative Care.2015b)*.* There were two further publications charting the progress of the living and dying well report, the first of which *Living and Dying Well- Building on Progress* was published in 2011. It outlined achievements that demonstrate the provision of high quality palliative care is being rolled out across Scotland. It was also the first time the focus started to shift to the staff providing the care as the report identified that health boards have a responsibility towards their staff who were caring for the dying (Scottish Government. 2011).

A second report titled *Are we living and dying well yet?* suggested that the community in Scotland was not living and dying well and that there was huge scope for improving palliative care further. The report went on to recommend the development of a Strategic Framework for Action which should be broad based and far reaching and delivered as soon as possible (Marie Curie Palliative Care Institute & Scottish Partnership for Palliative Care. 2014).

2.4.3 Developments following the use of The Liverpool Care Pathway

The Liverpool Care Pathway (LCP) was listed as a tool of choice in delivering the five aims of the living and dying well report. The LCP, an integrated pathway for end of life care was developed in the Royal Liverpool University Hospital together with the Marie Curie Centre in Liverpool, and the aim of The LCP was   to transfer elements of best practice from the hospice model to healthcare areas such as hospitals and communities (Marie Curie Palliative Care Institute. 2010). It allowed a clear identification of outcomes

of care, which could be difficult to measure when caring for patients who were dying. It could also prompt end of life care decisions and facilitate communication with patient and families, leading to an improvement in care and symptom control (Walker and Read. 2010). The characteristics of an Integrated Care Pathway are that it is a multi-disciplinary plan of care based on evidence from research which incorporates local and national guidelines for care. It also forms a single record of care for use by all disciplines (Mellor et al., 2004).

The description of a care pathway and rationale for using it appeared to provide good evidence based practice in relation to the principles of palliative care. The document appeared to offer a solution to instilling the distinct tenets of palliative and end of life care in particular into an acute setting where clinicians may not be very familiar with the requirements of delivering good quality care to the dying. There were challenges however and in particular in relation to the public's perception of the LCP, and many media outlets reported the LCP led to poor practice and lack of care. The result was a public outcry and a call to remove the LCP from use (Chapman. 2009).

As a result, the UK government held an inquiry into the use of the pathway chaired by Baroness Julia Neuberger. The independent Neuberger review looked at the use and experience of the LCP in England and considered evidence from a broad range of areas including health professionals, academic literature, hospital complaints and members of the public. The report, published in May 2014 ; More Care, Less Pathway, A review of the Liverpool Care Pathway uncovered failings in the use of the LCP which correlated with three of the five main aims of the Living and Dying Well report (Neuberger et al., 2013) .

The three areas highlighted in this key report by Neuberger et al (2013) were the lack of development of specific patient care plans, the requirement to improve communication amongst clinicians and patients and the lack of provision of education and training on the use of the LPC for all staff in practice. The Neuberger review panel suggest that lack of training may in some part explain the reports of poor quality nursing care received by

patients. They went on to suggest that nurses should have a requirement to demonstrate proficiency in caring for the dying similar to the process applied to doctors (Neuberger et al., 2013).

A further area highlighted by the Neuberger report was the lack of development in research in end of life care, with well below 1% of research funding devoted to end of life care. The panel recommended that the National Institute for Health Research (NIHR) fund research into not only the biology of dying but also the non-physical facets as the conclusion of a life is also defied by its nature, content and connections within a society. The experience of dying should also be explored as critical and social health objectives must be understood which will allow insight into how patients and their families experience care at end of life. The report suggested that this would enable health care organisations to develop best practice and provide ways for the nurse to support the patient and their families providing help in understanding and acceptance of the experience of approaching death.

The Neuberger report went on to state that many of the problems encountered whilst using the LCP to deliver end of life care were a result of the clinicians being unaware of the guidance in care of the dying and a "*shocking unwillingness"* to discuss end of life issues. Observation was also made that everybody in society must be prepared to openly discuss death and dying in order to accept this as a normal part of life and therefore allow consistencies in the quality of care given to the dying. The report concedes that the government cannot change the way the nation thinks about death and dying but professional bodies can take a lead among their members and collaborate with organisations that promote public awareness of death, dying and bereavement (Neuberger et al., 2013). The LCP was subsequently phased out by the Scottish Government in 2014 (Scottish Partnership for Palliative Care, 2015b). The withdrawal of the Liverpool Care pathway did however cause some concern to nursing teams as they felt direction for delivery of palliative and end of life care was lacking and perceived their practice was called in to question.

Caring for People in the Last Days and Hours of Life (Scottish Government. 2014) was published in December 2014 after accepting the recommendation

from the More Care, Less Pathway report (Neuberger et al,. 2013). The rapid changes that ensued identified that leadership, measurement and support for implementation and improvement was of the utmost importance when phasing out the LCP.

The document aimed to guide healthcare providers across Scotland to facilitate end of life care to a consistently high quality. There are four principles set out to guide clinicians which are 1. Communication must be timely and sensitive as it is an essential component of each individual persons care. 2. Multi-disciplinary discussions must take place around significant decisions about a person's care such as a diagnosis of dying. 3. The individual needs of the person such as physical, psychological, social and spiritual are recognised and where possible addressed. 4. There should be consideration given to the carers or relatives attending the person. The four principles formed the framework for future planning and development across Scotland. The fourth principle mirrored the assertions from the *Living and Dying Well- Building on Progress* report, which stated that health boards have a responsibility to their staff caring for the dying (Scottish Government. 2011). As stated previously more palliative and end of life care is being delivered by generalist nurses in acute settings and health boards should ensure that the responsibility to care for staff delivering care to the dying extends to generalist nurses in acute settings, not only those in palliative and end of life care units.

 Following this the Scottish Government committed to develop a Strategic Framework for Action. This would be linked to the government's 2020 Vision for Health and Social Care, where people are able to live healthier longer lives in a homely setting if not able to stay at home. This will be supported by an integrated health and social care system.

The Scottish Palliative Care Guidelines were published in 2014 by NHS Scotland in collaboration with a multidisciplinary group of professionals working throughout Scotland. They reflect a consensus regarding good practice and their aim is to provide a usable format which was evidence based on a large number of clinical issues (NHS Scotland. 2014).

Following the withdrawal of the Liverpool Care Pathway the SPPC published a 2014-2017 strategy which aimed to promote the availability of high quality palliative care across Scotland for all patient groups and families who require it. (Scottish Partnership for Palliative Care. 2015a). The SPPC do concede there are many challenges as well as opportunities ahead including the consolidation of the achievements of the living and dying well report. The implications for nurses in palliative care is that there is a need for a new approach to delivering end of life care following the withdrawal of the Liverpool Care Pathway (Scottish Partnership for Palliative Care.2015b). The strategy aimed to again push the tenets of good quality palliative and end of life care into the acute setting.

2.4.4 The Strategic Framework for Action on Palliative and End of Life Care

The Strategic Framework for Action on Palliative and End of Life Care was published early 2016 by the Scottish Government and sought to address some of the issues identified through the independent review of the Liverpool Care Pathway. It was also a direct response to a resolution passed by the World Health assembly requiring all governments to recognise palliative care needs and make provision for it in their national health policies (WHO. 2014). Following consultation with major Palliative Care groups across Scotland the Strategic Framework was published which stated their commitment to work with partners to ensure that high quality palliative and end of life care is available to all who can benefit from it by 2021.

The framework outlined key actions that would support the provision of palliative and end of life care for everyone in Scotland. The hope was that the framework would drive a new openness around the culture of death and dying. More detail about the documents specific aims can be found in appendix 2. In summary it sought to improve the emphasis on strategic plans and research activities to enhance access to and improve quality of palliative and end of life care. A systematic scoping review of palliative and end of life care research in Scotland from 2006 – 2015 was carried out and published in 2018. The review found that whilst there was a steady increase in PEOLC research in Scotland in the last decade, they recommended

further research was needed into intervention, assessment and management. It also highlighted a need to research interventions for carers and bereavement support. This review confirmed the findings the authors conclusions that there were no studies carried out in Scotland around resilience or professional grief recorded in the time frame (Finucane et al., 2018). While carers and professionals are increasingly seen as central to the provision of high quality palliative and end of life care, research is needed to understand their experiences of working continuously with people dying. There is a distinct lack of research around generalist teams working with and providing care for the dying in acute settings.

2.5 Recognition of Changing Care Needs and the delivery of end of life care by generalist nurses in Scotland

The population in Scotland is ageing with a projected increase among the over 75's of 75% by 2031 (Scottish Government. 2008) Figure 2 shows the population is living longer and a consequence of age is a predisposition to long term conditions such as cancer, diabetes, dementia, cardiac conditions and stroke. Over 55,000 people die in Scotland each year and although specialist palliative care nurses may be involved in the care of many of these patients, many are nursed by generalist nursing teams. This changing demographic will impact on both the type of care delivered and the resources required to deliver it (Scottish Government. 2008).
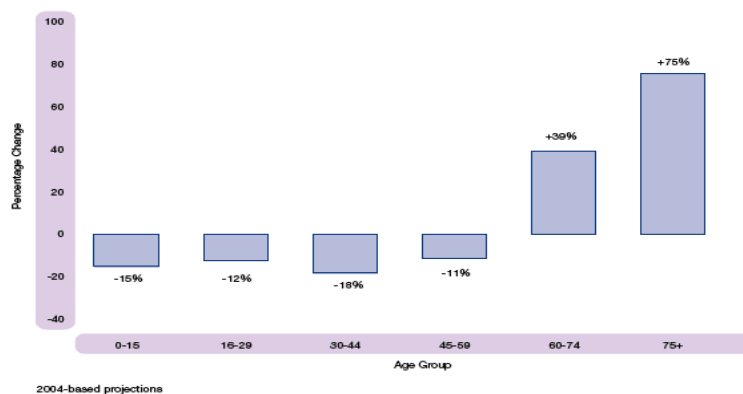
Figure 2 Projected percentage change in age structure of Scotland's population 2004 – 2031 (Scottish Government, 2008)

Palliative care applies to any and all conditions but the majority of palliative care in Scotland in 2006/2007 was delivered to patients with cancer. This is despite a cancer diagnosis accounting for less than 30% of all deaths (Mason et al., 2013). Patients with complex care needs other than cancer also need access to palliative care and this was identified by Marie Curie who changed its constitution to allow 49% of its services to be accessible to patients with any life limiting condition. This built upon the statement in 2004 from Audit Scotland that palliative care should be available to all patients not just those with cancer (Audit Scotland. 2008).

Mason et al. (2013) carried out a mixed methods study in three settings in Scotland, to identify how care is coordinated for patients with advanced progressive conditions in the last year of their life. Their ethnographic approach included an acute receiving unit in a regional hospital, a respiratory outpatients clinic and a large general practice.

A total of 198 interviews were carried out with patients, their families and carers, along with observations over 22 weeks. The results revealed, that despite efforts to transfer palliative care approaches into mainstream healthcare, very few patients in the study had been identified for palliative care despite being in their last few days of life. The team concluded that a model to improve coordination of palliative care must identify patients requiring referral to allow care to be planned and applied in a timely manner. The Strategic Framework for Action on Palliative and End of Life Care (Scottish Government. 2015) identified that a new openness around the culture of death and dying was required. The reluctance to discuss of end of life issues together with a less certain trajectory of illness and decline may account for the reluctance to transfer patients to a palliative care approach.

Care of the dying is a distinct component of palliative care but often carried out by generalist nurses (Allen & Watts. 2012). Generalist nurses are witness to, and have a wide experience of dealing with death in their role as primary caregiver according to Powazki et al (2013). Bradshaw (1996) in her opinion piece The spiritual dimension of hospice: The secularization of an ideal states that there are parallels between palliative care and generalist nursing care and that care of the dying is "quintessentially" the essence of

nursing as it is the time when nursing care is at its most important and fundamental. Bradshaw argues that an ethical ideal is fundamental to the compassionate and humane approach and delivery of palliative and end of life care. Nurses in certain areas do face death and dying more so than others, particularly nurses working in acute settings such as oncology or intensive care units according to Lagman et al who reviewed 1222 deaths in an academic medical centre in the USA (Lagman et al., 2006). Dolan and Holt (2008) suggest that emergency department nurses also face death regularly but also face more sudden deaths and the impact of care for the suddenly bereaved .

In contrast, emphasis in general nursing practice is placed on holistic nursing and assessment, with Katz and Sidell (1999) suggesting that caring for a dying patient in any setting is viewed by many nurses as "proper nursing" as it incorporates various aspects of good care. More so than any other discipline, nurses have a close and sustained contact with the dying person and can positively influence the well-being of the patient facing death (Allen & Watts 2012, Payne et a., 2008). They go on to suggest that Nurses have a close bedside position with the patient and so play an integral role in end of life care and are ideally placed to identify palliative needs. Walker and Read (2010) carried out a qualitative study using descriptive phenomenology to elicit the views and perceptions of nurses using the Liverpool Care Pathway from six practitioners in an ICU ward. One of the main outcomes of the study was the perceived importance of the nurse in end of life care. This outcome however could have been expected as the sample group were nurses delivering end of life care and would be expected to rate their involvement in the dying process as important to good quality care delivery.

More nurses in generalist settings will face death and dying and in order to enable the nurse to deliver good quality care and recognise their own support needs a holistic approach to support, education and competence around end of life care delivery should be adopted.

2.5.1 Identifying the need for holistic educational support for nurses delivering end of life care in Scotland

The seminal work by Kubler–Ross (1987) noted that clinicians trying to learn more about the final stages of life should try to get closer to their patients as those clinicians that do could discover how mutual and gratifying the experience could be.

Jack et al. (2004) carried out a survey to evaluate a palliative care network nurse programme which was set up in response to piloting of the Liverpool Care Pathway. It was a nursing programme designed to provide education to generalist nurses about palliative and end of life care working in acute hospitals in the UK. The findings suggested that whilst many nurses feel that they deliver good palliative care as part of their everyday work, many felt that they would or have benefitted from palliative care training. O'Hara (2011) used a focus group approach to gain nurses views on using the Liverpool Care Pathway in an acute hospital setting and reported that the nurses believed they did not have enough time to dedicate to the care of the dying. Living and Dying well (2008) state that palliative care is an integral aspect of care delivered by any health care professional to the patient living and dying with advanced or incurable conditions. It is also a tenet of this report that palliative care should start from an early stage, as the above studies indicate, that time at end of life care delivery is an important factor (figure. 3)
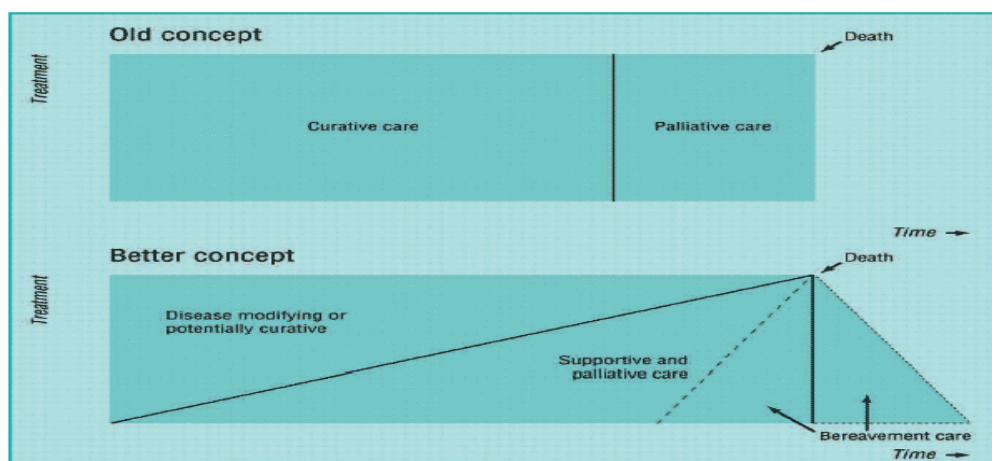
Figure 3 Introducing Palliative Care (Murray et al., 2005)

White and Coyne (2011) carried out a cross-sectional study of 714 members of an Oncology Nursing Society in the USA to asses end-of-life care core competencies deemed most important by the study group. The findings showed that end-of-life care was part of their practice and that education in this area was important however there was a consensus of opinion that they were not adequately prepared to offer good quality care in this area and in particular in the field of symptom management. They concluded that there were education gaps in end-of-life care programmes (White & Coyne. 2011).

The Nursing and Midwifery Council (NMC, 2008) does not have a specific code, guidance or standard for palliative care nursing. The code of conduct published on their website covers all disciplines and is stated as the foundation of good nursing and midwifery practice and should therefore apply to all disciplines. The More Care Less Pathway report published in 2014 pointed out that the NMC have no specific guidance for nurses caring for patients at end of life. (Neuberger et al., 2013). A revised code of conduct which came into effect March 2015 however does state that nurses should be able to recognise patients who are approaching death and be able to respond in a compassionate manner (NMC. 2015).

The SPPC in partnership with NHS Education for Scotland produced a guide in 2007 to support managers and individuals in identifying core competencies for use within their organisation (Scottish Partnership for Palliative Care. 2007). The aim of the report was to help individuals to make sense of how their knowledge, skills and development needs fitted in with the national context. There are a range of palliative care competency frameworks in existence including one from The Royal College of Nursing which provides a framework for nurses working in specialist palliative care. The competences have been graded over four levels (Royal College of Nursing. 2002).

There was however a lack of a consistent approach to palliative and end of life care education but this was addressed in the Strategic Framework for Action on Palliative and End of Life Care (Scottish Government. 2015). There was a commitment to ensure support to develop an end of life care educational framework for use across the whole of Scotland which drew

from and linked with the Strategic Framework for Action on Palliative and end of Life Care. It was acknowledged that palliative and end of life care is and will be delivered in acute settings by generalist nurses in greater proportions going forward. It was therefore imperative that education and support is set within a framework which can be used in any setting to give clear guidance and direction for future care.

This resulted in NHS Education for Scotland (NES) creating a Palliative and End of Life Care Framework to support the learning and development needs of the workforce in Scotland caring for people at end of life (NHS Education for Scotland (NES). 2018). The framework is far reaching and includes five domains of practice; the fundamentals of palliative care, communication, loss and bereavement, care planning and care in the last days of life. The framework does not however address the psychological and resilience needs of staff delivering palliative and end of life care.

2.6   Chapter summary

Chapter two provided an overview of the development of palliative care and highlighted that it was not until 1985 that it started to gain significance as a field of medicine in its own right.

Hospice and palliative care can be traced back to "places of welcome" provided by the early Christians to travellers and pilgrims requiring rest and respite it was aimed at injured travellers and the hopelessly ill and dying. The dying held a place of honour in the eyes of the Christians as they were seen as "spiritual pilgrims "who were close to God. In contrast the Roman model of hospitals that were built on military efficiency to enable speedy turnaround of injured soldiers and gladiators.

This separation of caring for the dying from other patients who cure seemed possible could account for the widening of the gap between care of the dying in a hospice setting and those cared for in an acute setting. The delivery and philosophy of care in both areas does not always align. The Christian model of care, providing sanctuary, lays the foundation for our understanding of hospice care today whereas the Roman model of efficiency and turnaround of the injured soldiers equates to a medical model of care.

The WHO has promoted palliative care and pain relief from the 1980's and since then a growing number of national associations collaborated to advance developments in palliative care and the integration with main stream service providers is presented as a measure of improved quality of care and could be viewed as widening the approach and philosophy of care into acute settings.

The developments in palliative care policy in Scotland continued with the formation of the Scottish parliament in 1998 and there have been a series of documents produced by the Scottish Executive detailing policy statements for the delivery of palliative and end of life care in Scotland.

The living and dying well report was the result of an extensive process of collaboration across Scotland (Scottish Government. 2008). Previously Hospice care was synonymous with palliative and in particular end of life care and this policy required a shift in focus for the acute setting. There was an acknowledgement that care of the dying was being delivered by generalist nurses in acute settings but no additional support for support for nurses delivering care in acute settings was offered.

Significant developments ensued following the withdrawal of the Liverpool Care Pathway. On face value the document appeared to offer a solution to instilling the distinct tenets of palliative and end of life care in particular into an acute setting where clinicians may not be very familiar with the requirements of delivering good quality care to the dying. However a report carried out on the use of the document concluded that that many of the problems encountered whilst using the LCP to deliver end of life care were a result of the clinicians being unaware of the guidance in care of the dying and a "*shocking unwillingness*" to discuss end of life issues. Observation was also made that everybody in society must be prepared to openly discuss death and dying in order to accept this as a normal part of life and therefore allow consistencies in the quality of care given to the dying. The report concedes that the government cannot change the way the nation thinks about death and dying but professional bodies can take a lead among their members and collaborate with organisations that promote public awareness of death, dying and bereavement. It is imperative however that

nurses caring for the dying must also be supported in awareness around death and dying.

In response to this the Scottish government published Caring for people in the last days and Hours of Life. The rapid changes that ensued identified that leadership, measurement and support for implementation and improvement was of the utmost importance. The Scottish Government committed to develop a Strategic Framework for Action on Palliative and End of Life Care. The framework outlined key actions that would support the provision of palliative and end of life care for everyone in Scotland. The hope was that the framework would drive a new openness around the culture of death and dying.

The framework also highlighted that while carers and professionals are increasingly seen as central to the provision of high quality palliative and end of life care, research is needed to understand their experiences of working continuously with people dying. There is a distinct lack of research around generalist teams working with and providing care for the dying in acute settings resulting in a recognition of changing care needs in the delivery of end of life care. It is also acknowledged that care of the dying is a distinct component of palliative care but often this is carried out by generalist nurses who are witness to, and have a wide experience of dealing with death in their role as primary caregiver.

More nurses in acute settings will face death and dying and in order to enable the nurse to deliver good quality care and recognise their own support needs a holistic approach to support, education and competence around end of life care delivery should be adopted.

Chapter 3
Literature Review

3.1   Introduction

In order to achieve the aim of the research, the guiding research questions developed were regularly consulted to ensure the literature review and search strategy remained focused and relevant. Three guiding research questions were developed :-

1.   What are the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying ?

2.   What is the palliative care nurse's response to the loss of a patient when working in acute settings?

3.   What is the meaning of loss and death experienced by palliative care nurses working in acute settings after the death of a patient ?

This literature review was undertaken in two parts. The initial review was undertaken in 2015 and took the form of a scoping review of studies pertaining to palliative care nurses delivering end of life care in an acute setting and their meaning making of loss and grief.

A further scoping review was undertaken in 2019 with the help and support of the clinical librarian at NHS Borders to ensure rigour and quality and help identify any further research carried out since the first review was undertaken. The scoping review was a process of dissemination to identify research gaps in the existing literature and were structured around the methodological framework discussed by Arksey and O'Malley (2005). Their framework incorporates five stages. The first of which is identifying the research question and then next to identify the relevant studies. Selecting the studies and charting the data account for stage four and five and finally collating, summarizing and reporting the results is stage five. This framework is used to identify gaps in evidence where no previous research has been carried out in the specific topic. The aim was to identify in-depth and broad results which included all relevant literature, even that which may not meet

strict predefined study design parameters. The process is not linear but rather iterative by design and therefore a justification was made to re-run the literature search using wider search terms to identify otherwise excluded studies which may have relevance to the particular topic.

3.2 Search Strategy

In the initial search the author identified primary data by searching electronic databases using EBSCO Host. These were AMED, CinAHL, Medline and PsycINFO. These databases were chosen because they included papers relevant to the topic area within nursing but also sociology and psychology and allied health professionals.

Key search terms used were, evaluation, definition and differences, followed by palliative, meaning, grief and loss. Palliative care nurse search term was added at a later stage.

For the search the author sought to identify all published retrospective and prospective primary studies in the English language from 2000 to 2015. The starting date was chosen to reflect the emergence of palliative care as a speciality.

Using the first search terms, a total of 377 articles were identified. The abstracts were reviewed and a total of 116 papers were included. However, after further refining using the additional term "nurse", the final number included was four. Therefore based on the search, 116 citations were identified but only 4 referred to palliative care nursing and had a loose connection to the subject matter of grief and meaning making. The citations referred to studies carried out with oncology, care of the elderly or paediatric nursing. No citations were identified which specifically looked at the grief palliative care nurses experience whilst delivering care in an acute setting.

Due to the initial poor results reflecting the paucity of research in palliative care generally a scoping review was identified as the most effective way to gather further evidence and so a multi method approach was then taken. A Scoping review allows the researcher to ascertain if the topic is viable and if there had been any previous research in the area. In addition a scoping review would identify any previous review of research area. It would then

support narrowing of the field of research to support a focused idea and clearly identify gaps to contribute to a clear understanding f what the value of the work will be. Therefore, the point of a scoping review is to be as comprehensive as possible to identify primary studies and reviews which would support answering the research question. The intention was to map themes and fields of interest against the research area, not rate the papers (Arksey & O'Malley. 2005). To address this a strategy was adopted which would enable identification of further research evidence through different sources. This strategy included consulting seminal works on palliative and end of life care prior to the date parameters set for the literature review. Further hand searches of key palliative care related journals were undertaken. A number of additional resources were identified through reference lists of articles identified, finally a review of conference proceedings and relevant networks identified a general trend in palliative care development, and where documents were published, these were reviewed. No research that specifically focused on palliative care nurses and how they make meaning of death and loss when working in their clinical role within an acute setting was identified.

A second literature review was undertaken in 2019 with the clinical librarian at NHS Borders. For the second search again the author sought to identify all published retrospective and prospective primary research studies in the Beyond the inclusion criteria described there were no exclusion criteria set to ensure a wide breadth of material. English language from 2000 but the inclusion date was extended to 2019. The Detailed searches drew literature from four electronic databases. These were CINAHL, MEDLINE, PsycINFO and EMBASE.

Key search terms were identified and used in combination to identify relevant studies. Search terms included palliative and end of life care, attitude to death, grief, making meaning, nurses, acute. Search terms of Hospice, oncology and community nursing were also included to expand the results even though this study was concerned with nurses in acute settings only.

A total of 700 papers were identified across the four databases. The titles and abstracts were then screened for relevance to the study topic. Duplications were removed and this resulted in 60 citations which appeared relevant. A further more in depth review was then undertaken and only 5 citations were selected for inclusion. The five citations however, reflected the results from the previous literature search and pertained to grief experienced by nurses delivering end of life care in other settings besides adult acute wards. A prisma diagram (Figure 4) outlining both searches is presented.
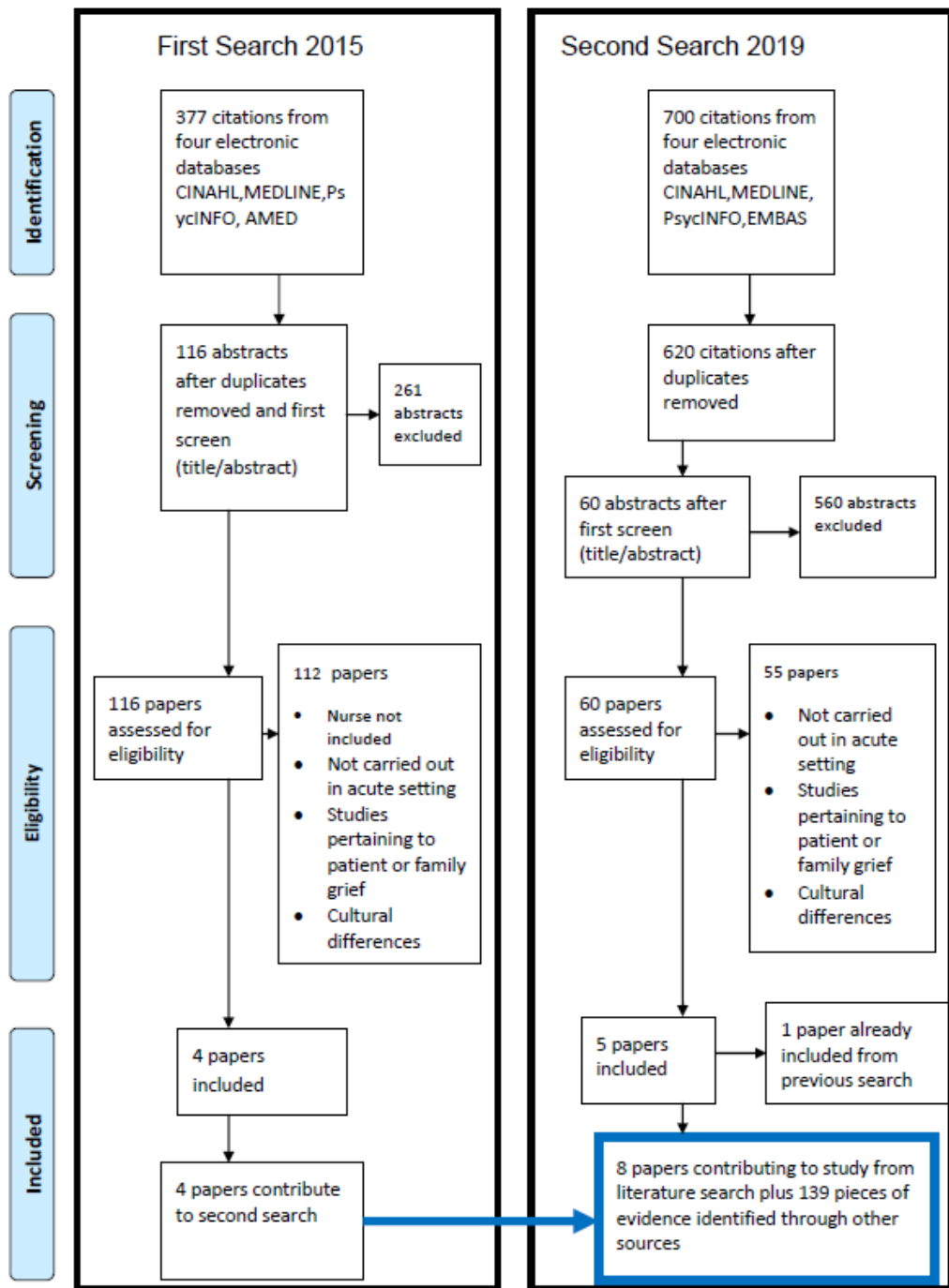
Figure 4. Prisma diagram

Section 3.3 will present a critical review of the papers identified in both searches and evidence found through other sources to inform the research and help to understand the extent of current knowledge about the concept of professional grief that palliative care nurses in an acute setting may experience whilst delivering end of life care and care after death. The

starting point of the review is the act of caring for the dying and the lived experience of the nurse delivering that care.

3.3   In Search of a good death

3.3.1   Is there such a thing as a good death ?

A good death means many things to many different people, depending on context, relationships, values and norms. A good death in this context refers to the quality of death the patient experiences, as defined by the nurse, as a direct consequence of the care that is delivered by the nurse as death approaches.

The aim of a nurse delivering end of life care is to ensure the patient can experience a good a death as possible. The lived experience of professional grief that the nurse experiences whilst ensuring the patient experiences a good death is bound up in their own attitudes to death and dying. Their response to the loss of a patient and the meaning of that loss and death impacts and affects their delivery of care and the meaning they make of that loss. Good and death however are difficult words for many to combine or envisage together. Dying is a natural process but for some it remains a taboo subject and discussing the topic can lead to apprehension and fear resulting in poor communication and misinformation for patients, carers and health care professionals alike (Chapman. 2009). The apprehension to discuss death and dying may be in some part due to lack of exposure to somebody who is dying or an unwillingness to face the coming loss experienced.

 Patient and family experiences may be affected by a lack of familiarity with death in modern society (Scottish Government. 2008) as generations now are less likely to live together in an extended family environment where elderly relatives were cared for in the home by the younger generations. Elderly relatives are more likely to live away from the family and death frequently occurs outside the family home. This can result in a cultural resistance to the acknowledgement of death whereby the natural process is not easily accepted and cure rather than care is sought for loved ones

(Scottish Government. 2008). Death has become medicalised with the establishment of the NHS resulting in free healthcare for all. From the 1950's the preferred place of care and death was in a hospital setting however the evidence today points towards more people dying at home or in a homely setting (Marie Curie. 2018)

This lack of familiarity in turn impacts on the delivery of end of life planning and communication. The consensus of the living and dying well report (2008) was that as a society we do not discuss death and dying enough. In addition Schenck and Roscoe (2009) in their paper examining the relationship between aging, time and the course of life in regard to death suggest that currently some people do want to find meaning in aging and dying, asking questions such as

 "what it means to die well and how this may be accomplished" p 61

These questions form part of larger debates amongst both the general public and government departments concerned with policy and medical care.

Watts (2012) carried out a critical commentary of end-of-life care pathways used to support and promote a good death and reminds us that it is a prominent social and political priority to achieve a good death but also a fluid concept. As health care professionals we strive to deliver care which will enable or facilitate a good death but this intention may not always be straight forward. A good death is not one dimensional with many different characteristics to consider according to Katz and Sidell (1999) who write about this in in Easeful death, caring for dying and bereaved people. It is a concept that may be defined differently by each patient but includes common components such as pain and symptom management. Keene et al. (2010) report that nurses who witnessed their patients undergoing aggressive and invasive treatments, although they were in the dying phase caused emotional distress to the nurse and they sought instead to manage their patients symptoms and relieve their pain. In her chapter on a good death in Key Concepts in Palliative Care, Baldwin (2011b) reminds us that there may also be contentious issues which the multidisciplinary team need to address and discuss. A whole range of needs such as spiritual, emotional, practical and physical needs require addressing. This reluctance to discuss

contentious issues may contribute to the apprehension to discuss the forthcoming death.

The End of Life Care Strategy (Department of Health 2008) describes a good death as one where the patient is treated as an individual with respect and dignity. The absence of fear and pain and being surrounded by loved ones in a familiar place are also key requirements.

In order for the patient to be treated as an individual with respect then the health care professional must maintain integrity and self-awareness which is key to delivering good end of life care according to Buckley (2008).The nurse should be self aware and aware of others in order to understand the needs of those in her care. Those needs are often not vocalised due to a reluctance to discuss death and dying or apprehension and fear. The needs of the patient and their families must be considered at all times and lack of understanding , on the part of the nurse may lead to compromise and affect the quality of care given. Due to the reluctance by some to discuss death and dying, even with the clinical team, intuitive care is necessary to meet their needs. Smith et al. (2012a) however found a creative and supportive way to address this problem. They carried out an initiative in North Tees and Hartlepool NHS asking family members to complete a diary of care so feedback could be given to staff members in real time, with the hope that issues raised could be addressed immediately (Smith et al,. 2012a). This initiative would allow the patient and those important to them to raise any hopes ,fears or concerns with the clinical team through the use of the diary and in so doing pave the way for more structured and focus discussion around issues important to the patient and allow them to plan for a good death. This approach however may not elicit responses from the family members which are independently verifiable, as they could not give anonymous feedback and may hold back from describing instances of poor care for fear of causing friction within the team or instigate any potential negative implications of care.

A peaceful death with good communication and support for relatives is likely to result in a less emotionally upsetting experience for all concerned, including nurses, and could result in an easier bereavement period

according to Ellershaw and Wilkinson (2011). Other characteristics of a good death noted by Katz and Sidell (1999) include ensuring the social and spiritual needs are addressed. The patient may have unfinished business and should be encouraged to discuss any concerns and fears they have with the care delivery team if appropriate. By accepting the inevitability of death the patient is allowed to come to terms with his situation and is given the opportunity to do and say the things they feel are left undone. The chance to say goodbye and affirmation of affections may give peace to the dying patient and their family and friends and this is commonly perceived as contributing to a good death. The nurse must be skilled in giving the patient time and space to explore their wishes in a safe environment and in so doing can contribute the patients expectations of a good a death as possible. This assertion, whilst well meaning however may create unintended consequences if the patients expectations of resolving unfinished business is not resolved. They may also never accept the inevitability of death and the nurse could be left feeling as if they had failed the patient in some way.

Although the complexity involved in navigating the wishes of a person for a nurse is challenging, in order to open the difficult conversations around patients preferred place of death or cultural or spiritual requirements the nurse must first develop a trusting relationship. Their relationship with that person may have developed, or is developing in a relatively short period of time (Ellershaw & Wilkinson. 2011). The breadth and depth of that relationship however can become very rich and lay the foundations for a mutual respect and trust which may impact on the perception of achieving a good death.

To feel that the they have delivered care in such a way that facilitates the social priority of a good death nurses need to be able to navigate many layers of emotions, thoughts, feelings and values of both the patient and themselves. These are also underpinned by confidence, competence and knowledge. The following sections will discuss the elements that go towards the delivery of care in support of a good death.

3.4. The nurse/patient relationships at end of life

The physical aspect of nursing can be the starting point for developing a supportive and trusting relationship which will enable psychological support to be offered. This can result in the development of spiritual care according to Luker et al (2000). They conducted a study in a health care trust in the UK interviewing 62 nurses and examined how community nurses perceived quality when providing palliative care. The supportive relationship which delivered good spiritual care was seen as an important factor in their role. Wright (2002) focussed on the perspective of district nurses caring for the terminally ill. They established that supportive relationships were important in providing emotional support to the patient and their family through being open and honest. Haraldsdottir (2011) suggests that the nursing team should be given opportunity to seize the moment and be with the patient to enable them to contextualise their nursing care and focus on the needs of the patient. Nurses within community settings however have much more scope to develop close relationships with patients and family members compared to nurses in acute settings. They are invited into the patients home and deliver care in familiar and comfortable settings for the patient which may contribute to a feeling of trust. Acute nurses within an inpatient setting may not have the opportunity due to resources, staffing context and time constraints meeting multiple demands to foster strong supportive bonds in order to feel they are adding value to the care they deliver

Campbell (1984) suggests the term "skilled companion" to describe the relationship a nurse has with the patient. Palliative care nurses need to be compassionate but remain within boundaries which can be very difficult when working closely with patients and their loved ones. This demonstrates the skills required to build authentic relationships but remain within their role as a nurse and caregiver. Actions and decisions taken in a personal relationship are usually based on emotions. The nurse must use knowledge and cognition, not emotional bias to form the basis for professional decisions (Anewalt. 2009). In contrast Keene et al. (2010) following their study examining grief reactions for paediatric nurses caring for dying children reported that the most distressing aspect of caring for the dying was when the nurse had developed a long term relationship with their patient or family

and the emotional distress that ensued for the nurse following the death of the patient. The nurses experience a loss of relationship not only the loss of their patient. Conversely the relationship with the family of the dying also rated highly as one of the most satisfying aspects of care. Caring for dying children does carry a different dynamic to caring for dying adults and whilst similarities can be drawn care should be taken that the nurses experience is taken in context to the patient group, family context and dynamic and setting.

Barbour (2016) comments that relationships develop between nurses and their patients and families and that after the death of the patient they do experience loss but often have no formal opportunity to grieve before moving on to care for another dying patient. Nunes et al. (2018) also recognise that nurses are affected by the experience of continuous loss. Barbour (2020) counters however that some nurses however may have an expectation that the loss of a patient is part of their job and they should be expected to move on with their work.

With this in mind nurses must however realise and accept that they personally and collectively also need self care and the skilled companion model should be applied to themselves as once they become true companions to themselves they can then become skilled companions to their patients (Tschudin. 1997).

A mature approach to life and death helps the nurse to keep things in perspective and maturity need not necessarily pertain to age but more depth of understanding and compassion. Life experience and growth of wisdom often equates to maturity far more than age alone however "being sensitive" can be deepened and developed through experience and advanced practice (Sayers & De Vries. 2008). Gambles et al. (2003) undertook quantitative analysis of 178 palliative care and cancer nurses. A questionnaire was used to undertake personality profiling to ascertain specific character traits within the selected group. The profiling found that the group showed traits of being gentle, emotionally sensitive and intuitive and the older nurses scored even higher than the younger nurses. They suggested that age had a potential to effect the way in which they connected with their patients and demonstrated how maturity allowed more effective connection and relationships to

develop. This quantitative study however may not have had the depth and breadth to fully explore and understand the nurses motivations and their attitude to relationship building that a qualitative approach would have taken.

The therapeutic relationship was also noted in the study conducted by Johnston et al. (2014) which explored the self-management support in the context of palliative nursing and is discussed further in characteristics of the palliative care nurse. Johnston and Smith's (2006) phenomenological study of the perceptions of patients and nurses of palliative care identified the importance of building therapeutic relationship skills in the nurse. This study carried out in Scotland, interviewed 22 patients and 22 nurses in two acute hospitals and hospices. Other qualities they identify as being essential for good palliative care nursing were kindness, compassion, warmth and genuineness. Cloyes et al. (2014) also pointed out the importance of building effective relationships following the conduct of focus groups with caregivers and nurses. Both these studies did not focus soley on nurses delivering end of life care in acute settings but included hospice nurses, carers and patients and so results would not be focused on the aims of this literature review.

Luxardo et al. (2014) carried out a qualitative research inquiry to describe the experiences of staff delivering end of life care, to examine how the staff viewed their patients and to undrstand how these experiences affected the daily lives of the staff. The study, undertaken in Soth America, included thirty staff members from a range of disciplines including physicians,social workers and nurses. Whilst the study was not specifically aimed at the nursing team, some similarities can be drawn. One aspect of end of life care that was identified within the group was that patients at the end of their life need to attain a deep and meaningful connection with others, and the desire for spiritual comfort and peace together with acceptance is very strong. This emphasis on relationship building suggests the nurse must gives something of themselves in this process. They go on to assert however the consequences of the nurse giving something or so much of themselves is unclear and the cost to the nurse has not been quantified.

The key learning from this section is that the physical aspect of nursing can be the catalyst for building trust and relationships. The nurse must however

have the skill to be authentic within the relationship but also remain within their role as a nurse and caregiver. The development of relationships with the patient or family can contribute to a sense of purpose and satisfaction however there is also the potential for emotional distress following the death of a patient. From the literature examined however it may be difficult to align the findings to this study in great detail as the subject matter is more closely aligned to hospice type settings and specialist palliative care.

3.5. Spirituality

The simple act of developing a relationship and being with a patient is also an important spiritual act in its self. By offering a caring presence to the patient the nurse identified with the patient and their suffering offering compassion and dignity during a very difficult and frightening time (Puchalski et al., 2006). Nurses deliver spiritual care to their patient through "being with" the patient and developing mutual trust and support. As far back as 1948 the WHO described health as more than the absence of disease but rather a state of wellbeing which incorporates physical, social and spiritual aspects (WHO. 2012).

 From these definitions we can see that health and wellbeing relies on many aspects of one's self. Wright (2005) states that spirituality is part of health and it is the bonding of spirituality and health which forms the basis for joy, sadness, health, illness, birth and death. There is therefore a strong argument for promoting spiritual care, and the understanding that spiritual care is a foundation of good basic care and support offered to patients.

In contrast not attending to a patients religious and spiritual wishes, where this is possible, could be viewed as discrimination. There is a regulatory framework which forbids discrimination. The Equality Act 2010 offers legal protection against discrimination against protected characteristics such as gender, age or religious belief (UK Government, 2010).

In addition financial aspects of delivering good spiritual care point to better patient outcomes and satisfaction which leads to better productivity and less stress among the health care team. Clinically there is some evidence that patients who are well cared for have a greater chance of good health, with

immune systems for example working more effectively (NHS Scotland, 2008).

According to Cox, Campbell and Fulford (2007) spirituality is viewed as an important element of palliative care and is an area that can challenge nurses in practice. Nurses often feel ill equipped to deliver spiritual care and view it as a separate component of care which they sometimes find difficult to place within a task based approach to care. Plante and Thorensen (2007) warn there is a danger that the patient may be seen as an object and their illness, a pathology or disease to be cured. Therefore an understanding that the body and spirit work together and should be treated as a whole must be recognised by nurses. Siddique (2014) on behalf of the equality unit of the Scottish Government and the school of divinity at the University of Edinburgh carried out an online national survey in Scotland in 2014 to understand better the changing demographics of belief and religion within contemporary Scottish society and found that 75% of respondents felt that it was important to take account of personal spiritual care in healthcare and nurses therefore should be equipped to deliver spiritual care.

It is very difficult however to define what spirituality is as each individual has a different definition according to Milligan (2011). The Royal College of Nursing lists components of spirituality such as hope, belief and faith (RCN, 2011). This expands on the view of spirituality and religion being one and the same. Eliopoulos (2010) also points out that religion and spirituality are not synonymous. Spirituality is concerned with making connections which can provide people with hope, purpose and comfort according to the Department of Health (Department of Health. 2009). The European Association for Palliative Care describes spirituality as a dimension of human life that is dynamic and relates to peoples experience and how they connect with others or the sacred in the moment (EAPC. 2012). Through providing care and support through therapeutic relationships the nurse is delivering spiritual care .

Nurses often find the subject of spiritual care and the assumption that all nurses are capable and willing to offer spiritual care worrying and in some cases very stressful. Spiritual care is often closely linked to religion and

nurses generally feel they do not have the necessary experience to help patients (Milligan. 2011). Nurses can often identify patients in need of spiritual care through everyday observations. This is an intuitive skill but knowing how to offer support and care can be difficult for some who feel they lack experience or confidence in this area (Milligan. 2011).

The emotional labour required to nurse patients at end of life can have a big impact on the nurse and care should be taken to manage their own spiritual and emotional health. Plante and Thoresen (2007) argue the importance of the nurse attending to their own beliefs as facing death takes the nurse and the patient to profoundly intimate places. In the course of their care delivery palliative care nurses may face death and dying patients on a daily basis and their attitude to death is made up of a complex combination of past and present experiences, cultural, societal and philosophical views.

Gerow et al. (2010) conducted a study exploring the death experiences of 11 nurses in a wide range of specialities who had experienced the death of a patient. Their findings suggested that nurses experience grief for their patients, but in a very different manner to that experienced by family members and often find themselves in conflict. The need to remain strong and offer support on one hand whilst managing their own emotions following the death of a patient with whom they may have formed a connection can be very difficult. This study can provide insight into nurses grief but again the field of nursing within the study is wide and different disciplines with differing contextual factors which may carry differing attitudes and beliefs towards patient care and death. Remen (2006) suggests that if someone is a witness to loss and is immersed in suffering on a daily basis, then it is unrealistic for them not to be affected by it.

This section identified that good health is more than the absence of disease but incorporates spiritual aspects also. Nurses however, often feel ill equipped to deliver spiritual care but the act of "being with" the patient is a spiritual act in itself. Nurses should however attend to their own spiritual needs as facing death with patients' on a regular basis can take them to profoundly intimate places. Nurses delivering palliative care in acute settings may however find difficulty in achieving their spiritual need.

3.6. Compassionate Care at end of life

Compassion can be described as needing to care for one who is suffering with the motivation to relieve that suffering and Halifax (2012) suggests that compassion has interdependent components that are developed through various factors. Intention to produce an outcome but with insight into possibilities available allows the palliative care nurse to discern between the desired and most - likely outcome and therefore allows them to practice context-sensitive compassion.

The term nursing stems from the French and Latin words for "nourishing". The nursing archetype is that of nourisher and healer (Tschudin. 1997). Whilst the palliative care nurse can provide nourishment in the form of support for the patient and their loved ones the healing has to take a different form or perspective, that of healing the emotional or spiritual aspects of the patients pain. They must also allow the patients choice over their own outcomes, this may present challenges to the team as a whole if for example the patient decides for example not to continue with aggressive treatment which may prolong life for a short period of time and conversely the patient may want to proceed with every treatment option available even though they may be futile.

Risks due to professional challenges and their implications are present in all forms of nursing but options must be carefully weighed when considering patient choice at end of life. The nurse may not agree with the patients' decisions and therefore find it difficult to support patient and families wishes, however support must be given. Nurses feel they have a duty to care and start their professional care from this standpoint but a conscience – based approach also impacts and affects their delivery of care according to Brykczynska (1997). This duty to provide care must be broken down to understand the interpretation of duty and care within the context of palliative care nursing. Setting realistic goals and allowing the patient just to "be". Through non-judgemental actions which are objective and controlled, the

palliative care nurse can be the patients advocate and through sensitivity promote their feelings of confidence ,dignity and self-worth (Sayers & de Vries, 2008).Although loss does affect nurses they must allow themselves "not to be a rescuer". The desire to heal and rescue patients seems implicit in other forms of nursing but nurses in palliative care must play a different role according to Tschudin (1997) when discussing the emotional cost of caring.

Bolton (2000) identifies that skilled management of emotions is valued as part of the nursing process. Emotional labour describes the way nurses work hard on their emotions to ensure they portray a professional approach however emotional engagement can also be altruistically motivated. Bolton's study explored how gynaecology nurses presented themselves to patients. The study identified that these nurses offered additional acts of thought and care to the patients which were not part of their job description but they believed were intrinsic in their identity as a professional carer. Bolton goes on to describe the act of offering additional emotion as a gift, freely given without expectation of return. The nurse however cannot truly share in the grief of their patients according to Bolton (2000) as they must maintain a professional demeanour.

In emotionally intelligent living Bharwaney (2006) suggests that to enable the nurse to offer empathy to the patient a degree of emotional intelligence is required which will facilitate a therapeutic relationship. Emotional intelligence is the ability to tune into emotions of one's self and others. The ability to understand those emotions leads to taking appropriate action on the emotional content that is found and should ideally be part of every experience and conversation.

A nurse requires the ability to empathise with and understand others and as such requires a strong degree of emotional intelligence to enable them to offer their best (Zirkel. 2000). The central thesis of the social intelligence perspective is that people reflect and are thinking beings. Their behaviour is reflected and can be understood in the manner they endeavour to engage with their environment socially, and then actively pursue desired outcomes in areas which are important to them according to Zirkel (2000). Beauvais

(2012) suggests that nurses are mindful of patient's reactions and the emotions patients experience and use this information to empathise with the patient and understand the patient's needs. In his study of personality traits for palliative care nurses Gambles et al. (2003) found that the most notable trait was emotional sensitivity with empathy and insightfulness. People who fall into this bracket often rely on their empathic understanding and are described as sensitive and compassionate and attuned to their own needs. The concept of emotional intelligence is linked to this personality type and they tend to have the capacity to recognize their own feelings and those of others and can manage emotions well (Gambles et al., 2003). It is also necessary for the nurse to remain aware of her own values and beliefs and to ensure they do not project her views onto the patient or ignore their needs (Plante & Thoresen. 2007). Keene et al (2010) however state that paediatric nurses caring for dying children report that witnessing the parents pain at the loss of their child had significant impact on their own emotional wellbeing. The assertion that Bolton (2000) makes that nurses can not truly share the grief of their patients and their loved ones could be difficult to adhere to in such circumstances.

Rolfe and Gardner (2014) in their commentary piece suggest that some people join the nursing profession already equipped with a well-developed sense of compassion, conversely some do not have this compassion and may never develop it. They go further, proposing that it is not possible to teach compassion. Compassion however is often understood to be an expression of values, beliefs and behaviours. It is not a competency or skill to be learnt. Being able to identify this lack of compassion early on in their career would be beneficial in signposting the novice nurse to a career which would be more appropriate. Raising awareness of values and understanding one's own beliefs would be a more accurate way to describe development of compassion within a clinical role. Similarly resilience is also an important factor and Cherny (2009) states that

"By *virtue of self-selection, clinicians choosing to enter into a career of palliative care often have a strong perception of personal resilience. We have, for the most part, chosen our work and we are thus self-interested*

partners in developing and preserving our ability to function, to contribute ,
and to rise above the suffering we help relieve" (Cherny. 2009). Pg 112

Nurses may have little control over the emotions experienced by patients but according to Randall and Downie (2010) they should try to understand their patients emotional state. The desire to understand their patients can be described as empathy, defined as being able to sense accurately and appreciate another person's reality and then go on to convey sensitivity. If compassionate care is to be effective and in order to address emotional support needs then good verbal and non-verbal communication skills are fundamental, according to Friedrichsen, Strang and Carisson (2001) who explored the experiences of family members who had received information regarding the withdrawal of active treatment for their loved ones. Sayers and Vries (2008) state that through good communication appropriate responses can be expressed which may include physical aspects such as comfort and touch or emotional responses such as understanding and promoting self-worth..

Compassion can be described as needing to care for one who is suffering with the motivation to relieve that suffering. People reflect and are thinking beings and as a person who is a nurse they have a desire to understand their patients. Compassion relies on the nurse being able to sense their patients' reality and through good communication skills, convey sensitivity towards them. Compassion therefore is an important factor when delivering end of life care and is intrinsically linked to emotions, values and intent to care.

3.7. The importance of communication when delivering end of life care

Death is frequently the last taboo and Chapman (2009) argues that poor communication can contribute to misunderstanding and a perception of poor care. Communication is important in all disciplines of nursing but good communication is central when delivering palliative and end of life. Cooley (2006) suggests that the subject of communication always arises when palliative care is discussed.

Skilbeck and Payne (2003) conducted a critical examination of the literature surrounding emotional support and care offered by palliative care nurses. Their findings confirmed that communication is one of the most important aspects of nursing care. Dosser and Kennedy (2015) purport that improving support for nurse which includes clear communication strategies to interact with patients and families at end of life is a main expectation in emerging palliative care services. They conclude that as anticipatory grief is an important factor in the transition to bereavement then support and in particular good communication skills are required from the nurse. The perception of a good death can be greatly influenced by the communication skills of the nurse. The nurses search for a good death therefore is tied in with the experience of the patient and their loved ones and by delivering good clear communication they aim to move towards that goal.

Poor communication and engagement have been cited as the two main complaints made by patients and their families to the Patients Association in recent years with an increase of 37% concerning communication and staff attitudes (Waters & Whyte. 2012). This data reflects all healthcare settings but communication difficulties can become more acute when delivering palliative and end of life care. Further training in communication with cancer patients was reported as the most frequent request by newly qualified nurses (Skilbeck & Payne. 2003).

Communication skills should be a key component of undergraduate nurse training according to Waters and Whyte (2012). Dosser and Kennedy (2012) carried out a qualitative study in Scotland exploring the views of nurses and bereaved carers in relation to support at the end of life. There were 13 bereaved carers and 23 nursing staff from an acute hospital ward. The findings confirm that communication skills are required by all healthcare practitioners but for those in specialist nursing roles, they require the necessary skill and knowledge to hold difficult conversations such as those at end of life. Dosser and Nicol (2014) also suggest that conversations with patients at end of life can be difficult for nurses who may lack in education in communication skills. The unskilled nurse may in fact give false hope or make inappropriate comments in a bid to protect the patient, their loved ones

or themselves. The need for clear information is a common theme amongst people receiving end of life care and their carers according to Beaver et al. (2000). Their qualitative study carried out in the UK looked at the views of 15 people with a terminal illness and 29 carers. They reported that lay carers in particular did not receive adequate help and support in the form of clear information which would allow them be effective in delivering care.

Excellent communication skills are required in order to deliver information in a way in which the patients' families will understand and digest according to Eyre (2010) the aim of the health care professional is to address each need in a sensitive but efficient manner and maintain the autonomy of the patient when communication or cognition issues present problems. Eyre (2010) indicated that family members may not always understand the information being offered or may have difficulty accepting the truth. In addition their requirements may differ to the patient and change over time. There is often a common misconception that the patient and family are in denial, rather than simply not understanding the disease process. The nurse must first asses their ability to understand and their readiness to accept any information given (Campbell. 2012). Chambers and Ryder (2009) also suggest that the nurse must be self-aware in knowing when to engage with the patient, offer empathy or be more factual. This should result in less distress for the patient. The benefits of allowing families to be involved in decision making through good communication include improved coping skills and confidence in the health care team. A lack of understanding of the families and patients' needs can lead to compromises and may affect the quality of care given (Smith et al., 2012).

McSherry (2006) in his text on spirituality in nursing and health care practice identified three skills required to ensure effective communication. These are 1. Attentive listening which focuses on what the patient has to say and picking up verbal and non–verbal cues. 2. Non-verbal communication such as facial expressions, body language and presence or giving time which is being with the patient in a spiritual, physical and psychological sense and 3. Active listening, which requires sensitivity and skill and allows the patient to come to their own conclusions so they feel able to decide what it is they wish to pursue or discuss or accept the inevitability of their illness and death.

Smith (2012) suggests that communication that is skilled and sensitive can help the nurse, without the need for them to preach, as patients are vulnerable and it is morally wrong for the nurse to promote their personal viewpoints or convictions. Sayers and Vries (2008) carried out a study looking at sensitivity in palliative care nursing and found that being aware and an effective communicator were central to being sensitive. Being aware consisted of active listening, observation and openness and transparency which helped the nurse to react effectively. In some sense this could be described as altruistic in nature which in turn enhanced communication.

Parker et al. (2007) conducted a systematic review of the literature surrounding end of life communications with adults and their caregivers. A total of 123 studies up to 2004 were identified and analysed. Amongst the findings was that honesty in communication especially when delivering bad news, can present problems and concerns to the nurse. Judgement must be used together with skill in knowing when to proceed and when to gently close the conversation. Important factors to consider when imparting information in this situation are the timing and style of delivery. Patients do however need to be able to plan and make decisions about future care and place of death and in order to do this they must have honest information (Fallowfield et al., 2002). Their paper examining unintentional deception and misunderstandings taken from interviews between care givers and patients highlights the importance of truth in communication with patients at end of life.

Communication within the team is also important to ensure the patient's wishes are being met and care is delivered according to agreed goals. It is also important however to ensure the team functions as a coherent focused group, not only to deliver the best care possible but also to support the team members themselves.

The implications of this section are that death is often described as the last taboo and as such communication around death and dying can often be lacking in quality and clarity. Communication is one of the most important aspects of nursing care but misunderstandings can lead to a perception of poor care. The nurse must use their judgement and skill in knowing how to

communicate with the dying and bereaved. Clear communication within the multidisciplinary team is also crucial to supporting a good death for the patient and emotional and wellbeing support for the nurse.

3.8.   Being part of a team

According to Smith-Trudeau (2011) there is an increasing pressure on nurse leaders and teams to change and develop in the current climate of expected high performance in health care. Health care is becoming extremely complex in clinical and administrative areas and elements required for success are great leadership, fellowship and teamwork according to Wheeler and Stoller (2011). Amundson (2005) who looked at 20 interdisciplinary health care teams across 11 social care centres in the USA, suggests that the use of multidisciplinary teams in health care needs to be pervasive in order to ensure patients receive seamless and integrated care which is not fragmented. This study suggested that a positive, supportive and caring environment impacts on the team's effectiveness. This need for a cohesive team also relates to the field of palliative care where teamwork is a common theme amongst the literature. Whilst this study was conducted in America and some time ago the tenants of team working and good team cohesion apply to the UK and today's health care settings. Dobrina et al. (2014) suggest that palliative care is interdisciplinary in nature and health professionals necessarily overlap but that nursing roles are complementary to other health roles and hold a special role in providing quality of life and support to patients and their families. Speck (2006) however advises caution around promoting the use of interdisciplinary teams and suggests that if the patient is to expect good continuity of care then the team must be cohesive with strong leadership and commitment to each other with the common goal of person-centred care. Ireland (2014) also warns that leaders of multidisciplinary teams have a responsibility to create environments where younger and more inexperienced members of the team feel able and empowered to request help from senior clinicians when required. Donaghy and Devlin (2002) report that there is a value in teamwork in the palliative care setting as it helps to develop relationships, resolve conflict and enhance mutual respect and trust but their study suggested that it is also important to

have good support measures in place for staff. McCloskey and Taggart (2010) also propose that opportunities should be given to staff to avail of peer support, critical incident debriefing and clinical supervision. Keene et al. (2010) suggests that support from co-workers and sharing similar experiences results in reduced stress and a feeling of a wider variety of coping skills.

The patient is also a stakeholder within the team and must also be actively involved if the nurse is to make any impact on the psychological, social or spiritual condition to the patient. The patient must also not be passive if the process is to have any benefit. The health care team can only influence those aspects if the patient is in partnership with the team as the patient has the most influence over the control of his own psychological wellbeing (Randall & Downie. 2010). For partnerships to work and be productive then a therapeutic relationship which builds confidence is required. In her opinion piece Biley (1992) suggests that care must be taken that the patient is not pressurised into taking an active role in decisions regarding their own care if they are happy in a passive role as this could cause distress for the patient and low morale for the team.

Ireland (2014) suggests that to deliver good palliative care then clinicians must not only have values of humanity and integrity but also knowledge and skill and be able to work in effective teams. Keene et al (2010) also report that paediatric nurses caring for dying children rate good team collaboration as an important factor in ensuring a satisfactory outcome is achieved. Belonging to a coherent, supportive and functioning team will support improved quality of care for the patient and their loved ones and provide a safe and supportive environment for the nurse.

Key points from this section are that palliative care is crucially interdisciplinary by nature and as such clinical roles necessarily overlap. However nursing roles hold a special role in providing good quality palliative and end of life care, not least in part due to the close therapeutic relationship with the patient that can develop. Team leaders however have a responsibility to create supportive environments for more inexperienced members of the team to enable them to feel empowered. Support from team

members also results in reduced stress and a feeling of inclusion and empowerment for the nurse.

3.9. The nursing speciality of palliative care

Martinez (2011) suggested that the nursing speciality of palliative care is a recent development and that leadership in palliative care should be provided through defining the scope and standards of palliative care nursing for both palliative care nurses and generalist nurses. Palliative care can be described as a philosophy of care, but it is also a highly structured , organized system of care delivery which can be applied in any setting and integrated into general patient care or used by highly specialized palliative care nurses (Martinez. 2011;Payne et al., 2008). In the UK, palliative care is delivered in many settings, including the home, inpatient units, hospices and care homes. Services can be provided by the NHS, charities and local authorities. There currently is a focus on ensuring the patients preferred place of care and death are met and to this end primary care trusts endeavour to provide care for those patients and their families who wish to stay at home. There are several day care centres funded partly by the NHS and supplemented by charitable donations to support care at home (Twycross. 2003). Not all palliative care is delivered by specialist teams however and this should be taken into account when developing service delivery.

The characteristics of a palliative care nurse are discussed in the next section but it could be argued that the characteristics could and should be used to describe nurses who deliver palliative and end of life care rather than a palliative care nurse.

3.9.1. Characteristics of the palliative care nurse

Kennedy et al. (2014) conducted an integrative literature review to determine the current state of knowledge regarding the personality profiles of nurses in specialist areas. There is some evidence to suggest there was a relationship between personality characteristics, choice of speciality and job satisfaction. The review included studies predominantly from America and between the

years of 1965 and 2010, (Kennedy et al., 2014). The nursing profession had evolved considerably during that time and but an evidence base that reflects current nursing practices would be necessary if personality characteristics were to be used for any application to practice currently, according to Kennedy et al. (2014). Learning from the literature review can be used to inform the aims of this study in the absence of any current review of personality profiles.

As part of a large three year research project looking at the characteristics of hospice workers, Amenta (1984) undertook a study to compare hospice nurses to generalist nurses. She wanted to answer the question of how hospice nurses were different to generalist nurses.   Amentia's study consisted of 36 hospice nurses and 35 generalist nurses across six different units or hospitals. According to Amenta   palliative care nurses are an "*autonomous professional*" group. This group had many similarities to generalist nursing, requiring many attributes such as knowledge, skill, compassion, effective communication and empathy to name a few. However for the hospice nurse group, the ability to nurse within a particular environment within unique constraints of time, choices and outcomes presents a very different approach to providing quality care to patients and their loved ones in an acute setting. Amenta (1984) described palliative care nurses as significantly more assertive, independent, forward thinking and less conventional than their counterparts in an acute settings. These set of traits are necessary to thrive within an "autonomous professional" group. The study also showed that hospice nurses are more likely to be deeply religious and have a high sense of spiritual significance. They also had a high self-rating on physical health and purpose in life score. These scores characterized them as robust and optimistic with confidence and a feeling of being in control of their life. Taylor et al., (1999) conducted a study to look at predictors of oncology and hospice nurses spiritual care perspectives and practices and also found that hospice nurses self-reported significantly greater personal spirituality. In contrast to Amenta's findings where hospice nurses reported themselves to be deeply religious, both groups in the study carried out by Taylor et al. (1991) reported that they were more spiritual than religious.   The study was conducted in 1981 and could be argued that the

findings may not accurately reflect present day nursing practice however Amenta's findings are reflected in recent findings such as the work of Johnston et al. (2014).

According to Johnston et al. (2014) an expert palliative care nurse has humane characteristics such as warmth, kindness and compassion. They have not only the ability but also the willingness to listen to the patient and their loved ones and helps the patient meet their needs through offering emotional support through the knowledge they have. Their study explored the self-management support in the context of palliative nursing and found that the palliative nurse enters into a unique therapeutic relationship with the patient. To achieve this, they require skills such as good communication and have received support around education in order to deliver good holistic care. Their study, whilst pertaining to self-care and palliative nursing also included key attributes of a palliative care nurse.

A concept analysis approach was used to gain a clear conceptual understanding of what self-management support within the context of palliative nursing meant. An international set of data were created to produce a list of defining attributes of the palliative care nurse. The list included attributes such as the supportive role of the nurse which allowed them to provide comfort and hope. They also provide an empathic relationship through "*knowing what they are doing*" and knowing what the patient needs (Johnston et al., 2014). They describe the process as a "mental representation" of a particular idea or phenomena and that it can be used as a stepping stone towards standardization within nursing and nursing language.

This process was evident throughout a mixed methods prospective study of 123 nurses carried out by Powazki et al. (2013) from a range of inpatient units including oncology, intensive care and palliative care. They asked questions about the nurse's self-perceived capability and comfort in care of the dying, their professional capability, and whether this was associated with demographic characteristics such as age, education level and gender. They found that the nurses with more experience in caring for dying patients felt more comfortable delivering that care.

This study reflected some of the findings from the study conducted by Amenta in 1984. The study conducted by Amenta (1984) stated that Hospice nurses had a high self-rating, but Amenta concedes that this may be due to better education and higher economic status similar to the findings of the study conducted by Powazki et al. (2013). Baldwin (2011a) describes one characteristic of palliative care nurse as the ability to build a relationship between the nurse and the patient. The relationship is a helping one where the nurse develops a therapeutic relationship with the patient providing holistic care which also encompasses the patients family and that attributes of palliative caring are companionship, compassion and competence.

Kirby (2003) identifies that a key characteristic of a palliative care nurse is the desire to care for others. This desire to care requires a commitment to reach out to others and emerges from a deep moral source from within oneself which compels us to act. Davies (2005) argues that to allow human beings to live together in harmony then helping each other and co-operating with each other is required and describes this as empathy. Davies goes on to suggest that empathy is necessary to allow one human being to understand another, to identify suffering and is crucial in palliative care. The need for empathy therefore contributes to the difficulty in delivering palliative care and contributes to emotional drain on nurses delivering it. De Souza and Pettifer (2013) suggest that the desire to care for others is deep seated and fundamental and that people who go on to choose a career in a caring profession recognise and identify with this desire within themselves.

Palliative care nurses are often described as autonomous and posses humane characteristics such as warmth, kindness and compassion. They offer emotional support through building empathic relationships. They provide holistic care which also encompasses the patients family and therefore attributes of palliative caring are companionship, compassion and competence.

A key characteristic of the palliative care nurse is the desire to care for others which requires a commitment to reach out to others and emerges from a deep moral source from within themselves. Empathy allows one person to understand another and this is crucial in the delivery of palliative

and end of life care. This need for empathy within end of life care however can contribute to a negative impact on the emotional wellbeing of the nurse. Emotional labour and drain can have far reaching implications for the nurse although a fundamental desire to care for others is often recognised and embraced by the palliative care nurse and compels them to work in this field. There could however be an impact on the nurses wellbeing which may in turn impact on their ability to provide effective care.

3.10. Chapter summary

Chapter three explored the concept of a good death from a nurses perspective. There are parallels between palliative care and generalist nursing care and care of the dying is "quintessentially" the essence of nursing as it is the time when nursing care is at its most important and fundamental.

In order to feel that they have delivered care which contributed to patients experiencing a good a death as possible, nurses need to feel confident, competent and knowledgeable. There are many emotions which the nurse will undergo throughout care delivery and these have an impact on their thoughts, feelings and wellbeing.

Relationships are fundamental in building trust with both the patients and their families. The nurse however must be authentic whilst remaining within their role as care provider and this can present emotional distress to the nurse when the patient dies and the relationships are ended. The accepted emotions experienced when a person undergoes a loss cannot be compared to the nurse patient relationship due to the complexities of the nurse being required to stay within the boundaries of their role.

Spiritual care is an important aspect of care which is inherent in the day to day process and act of delivering care to the dying. Nurses often feel ill equipped to deliver spiritual care to their patients but more insight into this would benefit their own emotional wellbeing, as the evidence identifies that nurses need to attend to their own spiritual needs. Compassion should be afforded to themselves and not only those in their care. Compassion is often

described as the need to care for one who is suffering with the motivation to relieve that suffering and could and should also apply to oneself.

Communicating with patients, their loved ones and the multidisciplinary team is fundamental to delivering good quality care. Skilled communication with the dying patient requires the nurse to know when and how to offer support and be aware that "being with" is a form of supportive communication. Communication with the multidisciplinary team is not only important to ensure an efficient and accurate discussion and provision of patient care, but also to ensure team cohesion exists, this importantly creates a supportive and nurturing environment for the nurse to practice and therefore opportunity to care for self.

As a person, the palliative nurse is often described as autonomous but with warmth, kindness and compassion. They have a desire to care for others which often emerges from within their own values and beliefs. Empathy is necessary but nurses should be aware of the impact of emotional drain when dealing with challenging or upsetting situations.

The culmination of the above discussion forms the description of the palliative care nurse and highlights areas where delivery of care and interpersonal relationships impact on the emotional wellbeing of the nurse delivering end of life care to the dying and deceased. As discussed at the beginning of this chapter the aim of the nurse delivering end of life care is to ensure the patient can experience a good a death as possible. The difficulties the nurses often experience whilst delivering palliative and end of life care in acute settings has been discussed and the challenges outlined. These challenges can contribute to the response to the loss of a patient and ultimately impact on the meaning of that loss and death. However this scoping review found no research that specifically sought to understand the grief experience of nurses working in acute hospital settings.

To fully answer the aims and objectives of the thesis, exploration of the context of grief and particularly within the professional realm is required. To this end, the following chapter will examine seminal and contemporary

directions in grief theory and explore previous work around professional grief before identifying factors that may affect the grief experience of the nurse.

The following chapter forms part of the literature review but for clarity and to clearly articulate the distinct concept of grief, a separate chapter has been dedicated to the discussion of grief. In this way the theories and discussion around grief as a phenomena underpin the discussion within the previous literature review chapter which examines the nurses search for a good death and associated contributory factors.

Chapter 4
Theories of Grief in context

4.1 Introduction

The previous chapter sought to identify the component parts of the experience of a good death, according to the nurse. External factors and the characteristics of the palliative care nurse contributed to their observations around the death of their patient. In order to understand how nurses experience professional grief following the death of their patient it is important to understand the separate phenomena of grief in general and professional grief in particular. The accepted models of grief are generally built upon understanding and knowledge gleaned from experiences of the bereaved in everyday life and not professional carers insights. There is a paucity of evidence for models of professional grief for palliative care nurses working in acute settings but some previous work around oncology and paediatric practitioners can offer some insight. The aim of this study is to explore and understand the lived experience of professional grief for palliative care nurse working in acute settings. This section aims to set the scene for what we know about grief theory in the general context now. Grief experienced by professionals will be explored but first an understanding of the seminal work around grief theory will be discussed to give context and background to the grief experienced by professionals.

Grief has many definitions that are usually attributed to the bereaved of a loved one or family member. Buglass (2010) however describes grief as a normal and natural response to loss, separation and bereavement which describes an individual's responses to loss with emotional and physical dimensions. The normal and natural response to loss from a palliative care nurse working in acuter settings will be explored further throughout this chapter.

4.2   Grief theories

There are many theories of grief and interpretations of the same theory. Probably the most well-known theory is that of Kubler-Ross (1987) who identified five stages; denial, anger, bargaining, depression and acceptance. Originally it was developed to help understand the coping mechanisms dying patients use at the end of life but has been used to map the emotions experienced by people grieving the death of a loved one. Kubler-Ross goes on to suggest that those who can get close to the "hopelessly" sick can discover that it is a mutually gratifying experience. They can learn a lot about the functions of a human mind and unique human aspects of our existence and therefore emerge with an enriched experience leading to fewer death anxieties relating to their own finality. This model does however attract criticism including that it is too linear and staged and does not reflect the constant changing emotions and perceptions of an individual. There is an argument also that the person may never reach the final stage of acceptance and experience death denial until the final stage when death occurs. Katz and Sidell (1999) state that patients may also appear to accept death in order to ease the suffering of their family and friends, in order to give the impression of a good death. A further criticism comes from Corr (1993) who suggests that the stages are too linear and represent defence mechanisms which do not allow for the complex attributes of grief to be fully explored and interpreted. Again this could point to death denial strategies continuing throughout the journey. Corr (1993) also argues that there is a difference of grief experienced by the dying person who may be grieving for the loss of their own future and concern for those left behind to the grief experienced by the bereaved person grieving for the death of a loved one and the loss of shared moments with them. Corr does concede however that in its defence, the model should be viewed in context and is merely one view of the grieving process

Lindemann (1944) developed a five stage theory of grief based on his clinical findings through dealing with people who have become bereaved following disaster. These are somatic disturbance, preoccupation with images of the deceased, guilt, anger or hostility and finally difficulty in

carrying out routine in everyday life. Lindemann identified two parameters for grief which are "normal" and "pathological" focusing on the intensity and duration of grief and the effect on social functioning. As grief however is so unique the pathological factors described by Lindemann have since been shown to be normal responses to grief for many people (Neimeyer et al. 2014). Lindemann also suggests that coping with grief or a significant loss requires the individual to become emotionally detached from the deceased which will allow them to create a new reality and adapt to their new environment in which the deceased is not included (Lindeman. 1944).

In contrast to this Bowlby (1973) suggested that attachments and bonds developed in early childhood are an important factor in the grief process. His four stage model includes shock, yearning and protest, despair, and recovery. The common human need to form strong bonds and attachments with others can cause severe distress when these bonds are broken. He believed the four stages must be worked through before acceptance is reached.

 Klass et al. (1996) echoed the findings of Bowlby and suggested that attachment can enhance attachment to the future when it is positive. Klass continued to research in the area of continuing bonds and conducted a cross cultural study in 2001 looking at continuing bonds as an aspect of bereavement in Japan and the USA. The study found that transforming the relationship with their loved one from living to a continuing bond relies on embedding the attachment to the deceased in a social network of bonds. Through maintaining a continuing bond with the deceased where the deceased plays a significant and ongoing part in their lives , survivors may achieve resolution in their grief (Klass. 2001).

Parkes (1998) also identifies similar stages of grief in his four stage model covering shock, yearning, disorganisation and recovery. He describes grief as a journey through incomprehension, denial, confrontation and resolution. He also agrees that theses stages are not linear but may be visited many times in any order due to external influences and triggers. Finally the bereaved person will adapt to the death through working through the various stages. Parkes (2006) discusses the concept of attachment theory which

originated in Bowlby's work, and describes how early childhood patterns of attachment influence the reaction to bereavement in later life. Other problems experienced by his patients not pertaining to grief were also found to be dependent on their early childhood attachments.

A task based approach to grief theory is favoured by Worden (1991) who appears to start at the last stage of the models discussed earlier. His model is based on moving from a passive stage of grief to active stages starting with task one of acceptance of the reality of loss. Task two is working through the pain of grief. Three is adjusting to a new environment and embracing change and finally task four is withdrawing emotionally from the deceased. Memories of the deceased must be maintained but the bereaved must be able to accept the loss and move on with their life. This models sits somewhere between Lindemann and Klass by stating the bereaved must withdraw emotionally from the deceased but maintaining memories should be encouraged, which could create conflict with the bereaved trying to detach whilst simultaneously trying to remember therefore causing confusion with which coping mechanism to use throughout the grief journey.

All the models have similarities in so much as they have distinct phases but do not have to be linear in their application, they may be experienced to different extents and intensities and varying periods of time by the bereaved and are influenced by external factors and triggers. Buglass (2010) in her exploration of the theories of grief however, argues that as grief is such a complicated process which is a unique experience for each bereaved person that trying to explain grief in a linear fashion is unhelpful. It may serve to give reassurance to the bereaved that their experiences are shared by others and show patterns and similarities in human behaviour. Ultimately however through trying to explain grief in a linear model there is no allowance for variation which may result in incorrect judgements on the right and wrong way to grieve.

In contrast to traditional linear models Schut (1999) propose a dual process model of bereavement. It is drawn from traditional models to present this model which purports a dynamic process which is fundamental to successful coping which they refer to as oscillation. This is the alternation between loss

and restoration orientated coping. It is described as a dynamic back and forth process where the bereaved are at times confronted by their loss and at times avoid thoughts and memories of their loved one and seek avoidance through other activities. In contrast to other classic psychoanalytical theories Schut (1999) acknowledge the benefits of denial providing it is not extreme or persistent. Over time through repeated confrontation and exposure the grief becomes habituated and reactions weakened. The central tenant of the model is that adaptive grieving entails confrontation with the reality of loss which needs to be addressed but not to the exclusion of other aspects of dealing with loss and should be experienced in measured amounts.

As discussed there are many theories of grief and interpretations of the same theory. All the models discussed however have a common theme of requiring the bereaved to undergo a journey of sorts, be that through a linear, stage or task based process. The feelings of loss encountered can often oscillate between opposing emotions and this in itself can present problems for understanding ones grief or may indeed contribute to resolution of negative and troublesome emotions. The bereaved become detached or work to foster continuing bonds, but what is apparent is that the journey of grief is often unique to the individual and influenced by their own experiences of the loss encountered. Whilst theses theories are discussed in the context of grief generally an observation can be made that several points raised and noted could equally apply to the experience of professional grief.

The following section discusses the continuing work around grief theory within the context of grief being a natural and normal response which should be understood and accepted as a natural response to loss.

4.2.1 Contemporary directions in grief theory

Neimeyer et al., (2014) reviewed the conceptual developments and emerging therapies following research carried out to challenge traditional conclusions and models of grief theory. He states that the consensus of opinion of grief theorists was that healthy mourning required "grief work" as

purported by Freud (1961). A process of letting go and painful review. The bereaved were encouraged to explore their grief and eventually move on through withdrawing emotional energy from the deceased and investing that energy into current and living relationships. Neimeyer suggests that recent research supports the establishment of ongoing bonds with the deceased and is thought to be a more realistic and healthier approach than detachment similar to the findings of Klass et al (1996). He suggests that the maintenance of emotional bonds with the deceased can be distressing or comforting depending on factors such as time since bereavement, an ability to make sense of the loss and their level of security in close relationships. These factors can be addressed using a two track model of bereavement which examines biopsychosocial functioning and the relationship to the deceased (Rubin. 1999). Alternatively they may experience the dual process model developed by Schut (1999).

The concept of a meaning reconstruction whereby the bereaved challenge their self-narrative which allows them to interpret the past, be present in the here and now and consider the future has been found to be beneficial (Neimeyer et al., 2014). Watson and Keegan (2007) wrote that contemporary thinking on loss and bereavement care is that resilience is a common response to bereavement as people are "well" by nature. Excellent end of life care, compassion and accurate well informed information on bereavement all benefit the bereaved and becomes part of their "story". Watson and Keegan (2007) go on to argue that meaning making characterises the modern approach to understanding bereavement and allows for the resilience approach appearing in themes today. The story involves actions from the past, lived experience of the present and forward into the future. Palliative care services are a transitory part of this story and need to respond to grief through meaning making. There are often challenges however in providing good quality end of life care in acute settings, with the expectations of patients and loved ones often not being met. The implication could be a negative experience of grief for all concerned including the nurse delivering care. To enable resilience to be fostered then understanding how nurses working in acute settings make meaning of loss and death must be explored and discussed.

The contemporary thinking on grief supports that the bereaved experience ongoing bonds with the deceased but continue to make meaning of the experience of the loss. Through examining their self narrative the bereaved can develop resilience, furthermore good quality end of life care, delivered with compassion and empathy can contribute to a positive experience for all including those delivering care to the dying. The following section carefully explores professional grief and draws some similarities to both accepted models of grief and the contemporary directions of grief support discussed here.

4.3   Professional grief

Luban and Katz (2016) remind us that health care professionals have their own accumulated values and beliefs around death and dying through their own histories of grief and bereavement. They go on to state that professionals need to review their own biases and experiences of grief. According to Brunelli (2005) all nurses should explore and examine the concept of the grieving process. Nurses are people first and the phenomena of grief is something that all human beings will experience at some point. It is also asserted that the grieving process should be understood among those delivering care to the dying. However Wisekal (2014) in her concept analysis of nurses grief describes the difficulties that nurses face when they experience the loss of their patient. The nurse does not experience closure the same way that families and those important to the deceased do. The nurse does not often attend the funeral or have continuing relationships with the bereaved to discuss memories and shared experiences. The room where the patient was cared for up to the death is cleaned and a new patient admitted sometimes very soon after the removal to the mortuary. Furthermore multiple deaths can occur in a short space of time resulting in a very quick succession of patients occupying the room. All these components do not allow time and space for the nurse to adequately apply understanding to their own grief.

Papadatou (2000) states that clinicians may experience loss for the patient, the family or even their own unmet goals and suggests that clinicians

experience vicarious grief for the family through identification with them. The clinicians own mortality may be examined or they may be reminded of their own personal loss past or future which may lead to the clinicians own beliefs being challenged. Papadatou (2000) proposed a model of the health professionals grieving process which conceptualises their reactions to multiple deaths of their patients see Figure 5. The model purports that grieving is an individual and social interactive process. The health professionals fluctuate between focusing on the loss and repressing or avoiding grief. This allows the health care professional to attribute meaning to the loss and invest in life and the living. This oscillation is described as healthy and only presents a problem when the clinician becomes fixed in either of the situations.
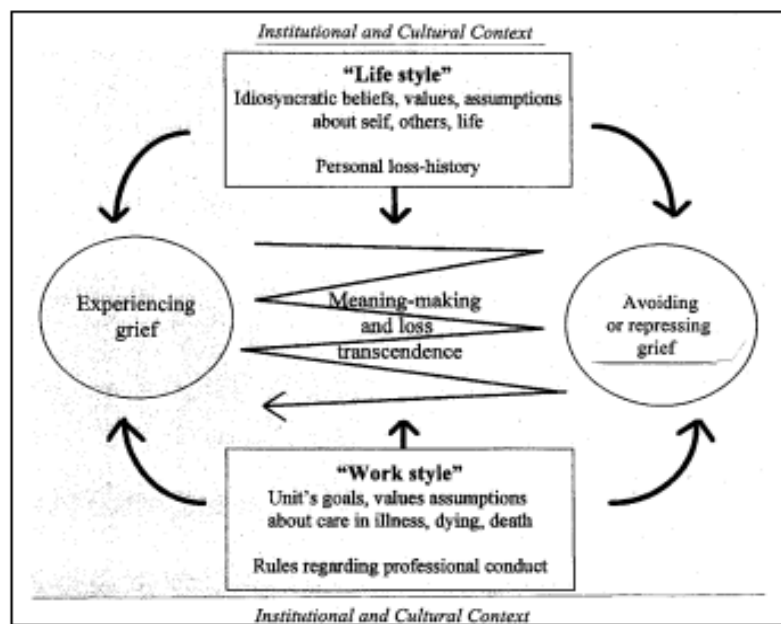
Figure 5 Health Professionals grieving process (Papadatou. 2000)

This model has some similarities to the dual process model developed by Schut (1999) in that it describes the process of oscillation between two states which could be described as positive and negative experiences. They purport that confronting the reality of loss in a proportionate manner contributes to adaptive grieving and a good outcome similar to Papadatou's assertion that oscillation can be healthy if proportionate.

A bereavement task model was proposed by Saunders and Valente (1994) which they developed following workshops and discussions with oncology nurses. The model suggested that nurses could successfully manage their grief through undertaking the tasks of making sense of the death, managing emotions and realigning relationships. They did acknowledge however that multiple deaths may make the tasks more difficult. This model has some similarities to meaning reconstruction theory proposed by Neimeyer et al (2014) and task based approach to grief theory favoured by Worden (1991).

Waskiewich et al. (2012) conducted an interpretive analysis of the meaning-making among 11 resident care aides (RCA) who provided end of life care in three residential care homes in Victoria, Canada. The study examined how the RCA's made sense of their experiences and demands on their emotions such as grief. The RCA's reported that they achieved closure through saying goodbye to the resident and spending time with them as they were dying. Conversely some reported coping by trying to detach themselves from the dying patient. Waskiewich et al (2013) state that this may result in poor care and that the RCA should be encouraged to acknowledge their grief and express their emotions and accept that this is an inevitable outcome of working in end of life care. The RCA should be encouraged to focus on the aspects of care they affect however subtle, as research has connected a high degree of satisfaction to the perception that good end of life care is being delivered and conversely frustration and dissatisfaction lead to a perceived failure to delivery of good end of life care.

Whilst the study was conducted in a residential care home with RCA's some similarities can be drawn on the process of meaning making experienced by palliative care nurses providing similar aspects of care such as personal care and being with the patient. The reality in acute settings however is that the palliative care nurse would not always have time to form relationships with the patient or those important to them due to resource constraints or working patterns. Patients receiving end of life care in acute settings generally do not have an extended stay with the average length of stay around two weeks. Spending time with the patient as they are dying and delivering good quality end of life care however would contribute to closure.

The study was also conducted in Canada which may differ to the cultural norms within the UK and the attitude to death and dying and nurse patient relationships may vary significantly to those of nurses in acute settings in Scotland.

Carton and Hupcey (2014) carried out a systematic review of the literature surrounding services available to address health care provider's grief. Only twelve studies were identified as being relevant and addressed interventions for clinician's grief. Each study was evaluated for quality and given a scoring of one to five. Studies that did not meet the minimum criteria of level three which demonstrated a high degree of rigour were excluded and those which were not research based were also excluded. This ensured the breadth and depth of the included studies met a strict inclusion criteria adding to the quality and rigour of the systematic review.

Nine of these addressed paediatric clinicians and Carton and Hupcey (2014) suggest that whist clinician's grief may be more profound after experiencing the death of a child, there is evidence of professional grief in many specialities. There is also a lack of representation for a full range of disciplines exploring the topic in the literature. They conclude that methods for addressing the grief experienced by clinicians has not been defined in the literature. They go on to suggest that there is a need for a more comprehensive definition and assessment of clinicians grief in general as well as the need to address clinician grief across a large range of disciplines. This systematic review did not address the experience of grief of palliative care nurses delivering care in acute settings as such but much can be taken from the findings to support contribution to this literature review. Not least the need to pursue research in the field of grief experienced by palliative care nursing in acute settings.

Doka (2014) states that part of bereavement care in palliative care settings must include staff care as there is a cost to those who care for the dying and bereaved. He goes on to say that they can experience grief reactions that have a negative effect on their personal sense of wellbeing. Continued exposure to stressful situations and experiencing multiple deaths of their patients all contribute to and inform the process of grieving for their patients.

Often to the personal and professional cost of the nurse delivering end of life care. Furthermore the implication of this goes beyond the need to care for the carer but could have adverse effect on the grief reactions of the bereaved if the palliative care nurse in acute settings experiences feelings of a negative sense of wellbeing and subsequently can not deliver care to the quality that they feel should be delivered.

The following section will draw on the literature and focus on the palliative care nurse and the factors which may affect their grief experience or be a consequence of their grief experience.

4.4   Factors affecting the grief experience of the nurse

Brunelli (2005) suggests that nurses caring for patients who experience long periods of suffering are often expected to help the patient and the family through those periods without sufficient support for themselves. They experience loss but are expected to "deal with it". Papadatou (2000) in her article discussing a proposed model of health professionals grieving process also recognises and warns of the potential for clinicians to experience compounded grief as they deal with multiple deaths and the cumulative nature of loss within a short period of time. The article follows the authors extensive experience as a clinical psychologist working in the field of paediatrics. This transcultural study was conducted in Greece and Hong Kong exploring the experiences of professionals working in oncology and intensive care. Sixty three in depth interviews were carried out to elicit the responses and findings from the study which resulted in the development of a health professionals grieving process model (see figure 5) discussed earlier in the chapter. The depth and breadth of the study contributed to the rigour of the research and help to inform the findings, however again the distinct role of the palliative care nurse working in acute settings is not particularly addressed but findings from the study are relevant to exploring and understanding the aims of this study

Many terms are used to describe the continued exposure to traumatic or stressful situations which lead to anxiety and harm to the professional delivering care. Freudenberger (1974) coined the phrase professional

burnout to describe continued exposure to stressful situations in many different professions. Furthermore Brunelli (2005) suggests that maladaptive grieving on the part of the nurse may lead to emotional distancing and burnout. Redinbaugh et al. (2001) assert that persistent exposure to caring for the dying and the deceased increases the strain on the health care professional and can lead to a profound sense of grief. These persistent exposures which result in a feeling of loss and grief are associated with occupational distress and burnout. Gerow et al (2010) suggest that nurses experience burnout due to the phenomena of unresolved grief and this results in nurses leaving the profession.

Secondary traumatic stress disorder or compassion fatigue were also a result of continued exposure to caring for the dying according to Figley (1995) who asserts that the clinician may mirror the traumatic stress the patient is undergoing. Gerow et al. (2010) notes that the grief process for nurses is different from the grief process of family members but their role is emotionally and physically demanding and this may push them to the point of exhaustion. They do experience high amounts of emotion when caring for the dying as they are expected to advocate for the dying in often futile situations. This results in compassion fatigue which must be recognised to enable the nurse to cope and thrive within a supportive clinical environment.

This theory has similarities to work carried out by McCann and Pearlman (1990) who describe the phenomenon of vicarious traumatisation as a disruption of the clinicians own beliefs following repeated exposure to the trauma of others.

Counter to this argument however, Sinclair (2011) describes the process of vicarious rehearsal in which clinicians reflected on their own death and dying through lessons provided by the patients themselves. Through facing their own mortality they felt more prepared for their own death and this may be a prerequisite for providing effective care to the dying. In order for this to happen however the nurse must be afforded time, space and support to undertake this reflection. Palliative care nurses delivering end of life care in acute settings are often task focused through necessity and little attention is given to their emotional wellbeing in a busy acute environment.

Transference is another concept that implores clinicians to examine their own humanness in the face of caring for the dying. Freud (1961) first described the concept of transference as an unconscious process which involved the arousal of the analysts unresolved conflicts and problems, it was regarded as something to be avoided and an obstacle to providing effective treatment. Transference however can be viewed as a phenomena which allows the clinician to be truly present, rather than being a theoretical intellectualization which describes transference as a problem to be overcome so that it does not present an obstacle to care (Katz. 2016).

She describes the experience of transference as normal and inevitable in clinicians caring for the dying but warns that it can become a dominant factor when patients and clinicians share common characteristics such as culture, ethnicity, age or family circumstances. She states that clinicians need to be aware of their feelings and ensure that they do not materialise in a destructive manner with the patient.

Dearmond (2013) suggests that hospice workers unconsciously and intuitively seek out encounters surrounding death and that these encounters may provide some preparation for their own death. It may also encourage a need to "heal" others and themselves, with the healing being understood as the healing of the psychological and spiritual rather than the physical aspects of the self. Dearmond (2013) asserts that through transference the clinician experiences personal growth and goes on to make a comparison with the myth of Asklepios and the wounded healer where the aspect of transference is notable with the patient seeking out a physician and the physician seeking out a patient.

In contrast Payne, Dean and Kalus (1998) stated that research suggests that Hospice nurses are confronted with the dying on a regular basis and assumptions are made that they are comfortable with the openness of acknowledgement of death and dying. Hospital nurses on the other hand were reluctant to spend time with dying patients and showed less acceptance of death and more fear and death anxiety. Payne et al (1998) made these assertions in 1998 and palliative and end of life care has moved from a hospice setting to acute settings in greater quantity since the study

was carried out and the same assertions may not be reflective of practice today. Dunn et al. (2005) carried out a study exploring the nursing experience of caring for dying patients with nurses practicing in oncology and medical units in America. They concluded that the more experience the nurse has with caring for the dying then the more positive the nurses care experience was. Expertise and experience allow the nurse to develop intuition and fostered a healthy attitude towards caring for the dying regardless of setting or area.

The different experience of death anxiety however between to two nursing groups may still be evident. Death anxiety is a negative emotional reaction which is brought about by an anticipation of one's own death (Peters et al 2013).Death anxiety is described by Neimeyer (1994) as a phenomena that is experienced in the ordinary every day situation and not where there is immediate threat to life. It has several components such as anticipating one's own death, fear of dying and the process of dying and the death of those important to them. Clinicians working in palliative and end of life care however are often in the position of dealing with their own personal feelings towards death and encountering death and dying on a regular basis within their professional lives (Payne et al., 1998). Neimeyer (1994) conducted a study to measure personal attitudes towards death. The study consisted of 504 respondents where a coding system was applied to their narrative description of their meaning of death. Along with fear of death and death avoidance there were three states of death acceptance examined. These were neutral acceptance, where death is neither feared or welcomed, approach acceptance, in which the participant had a strong belief in a happy afterlife and thirdly, escape acceptance where the participant believes that death was a welcome alternative to a life of suffering or pain. Ones personal attitudes to death influences how one lives their life. A high degree of neutral or approach acceptance resulted in happier more fulfilled lives and conversely those with a fear of death resulted in an inability to live life to the full. Personal attitudes to death anxiety therefore may impact heavily on the nurses response to professional grief. Peters et al. (2013) also asserts that providing care for the dying could be negatively affected by the nurses fear of death and they should be made aware of the impact of their own attitudes

to death in order to provide a supportive caring role. In response to these assertions a nurse is a person first with their own set of values and beliefs including personal attitudes to death and dying. These invariably account for the responses to a patient's death and their subsequent reflection on that death. External factors such as confidence, competence and lack of resources within a busy ward may also impact as much on their professional grief.

Doka (2014) also notes that there is a common theme to the various descriptions of the impact on the self of working in end of life care - the cost for caring. The cost of caring is a phenomenon which requires sensitivity, support and self-awareness to allow clinicians to recognise and deal with their grief. Emotional labour is another concept which similarly describes the cost of caring. Bailey et al. (2011) conducted an observational study with some in-depth interviews to explore how emergency nurses manage the emotional impact of death in emergency work. Although this study was carried out in a different field the results may be relevant. Bailey et al suggested that investing in therapeutic relationships with the patient, managing emotional labour and developing emotional intelligence all contribute to the nurse being able to find reward in caring for the dying which results in a more positive experience.

Funk et al. (2017) describe the concept of emotional labour as the work involved by clinicians caring for the dying. They assert that there is a need for the clinician to balance the needs of the self, other and the organisation in which they belong. Emotional labour involves the clinician managing and controlling their emotions, to ensure they are aligned with the organisational norms. Their study was conducted in a health care unit in Canada and followed an interpretative inquiry format. Twenty five participants both nurses and health care support workers from palliative and non palliative areas were included in the study. The findings showed that working with the dying was a source of emotional distress, that coping with grief required time and space and that grief suppression is a professional imperative. Grief was prevented through emotional detachment but this may lead to a form of unfinished business where the clinician was unable to show a grief reaction at work. Emotional self control was viewed favourably by many of the

participants but this conversely caused conflict with their view of themselves as a caring individual. They conclude that grief suppression can be indirectly promoted by organisations through inferred suggestion that an outward show of grief is unprofessional, furthermore heavy workloads result in less time and space to show and experience grief. They also recognise that nurses working in a palliative care setting had more opportunity to openly discuss the emotional impact of a patient's death however nurses working in other acute settings seldom had the opportunity. Both areas however were characterised by the same assertion that emotional restraint and suppression of grief was an expected norm. The study was conducted in one setting and the organisational norms and paradigms may have influenced the expression of grief for these participants. Assertions that all clinicians working with the dying display these traits can not be made although a study carried out by Hinderer (2012) found that critical care nurses did use emotional disconnect from patient death as a strategy to maintain normality. It is necessary to have some degree of emotional distancing to allow the nurse to continue with everyday life. Nurses delivering care to the dying and deceased undoubtedly undergo an array of complex and difficult emotional responses. Burnout, compassion fatigue and emotional labour are all consequences of continued exposure to traumatic or stressful situations. This may be compounded by vicarious traumatisation and transference which could result in death anxiety and lead to suppression of grief.

4.5   Chapter summary

There are many theories of grief and interpretations of the same theory with most models having a linear, stage or task based process. There is however a lack of evidence supporting theories around nurses providing end of life care in acute settings and the resulting subsequent barriers the nurses may face when trying to make meaning of loss and death in such settings. The experience of grief is unique and contemporary directions in grief identify that grief is a natural and normal response which should be understood and accepted.

In the course of their care delivery many nurses face death and dying. Their attitude to death is made up of a complex combination of past and present

experiences, cultural, societal philosophical, organisational and professional views. Nurses experience grief for their patients in a very different manner to that experienced by family members and often find themselves in conflicting roles, offering support on one hand and experiencing loss on the other. Complex and often difficult emotions contribute to their understanding of grief following the death of their patient. Care should be taken that extended exposure to stressful and traumatic situations around delivering care to the dying does not contribute to adverse emotional responses which may impact on their resilience and facilitate unresolved personal grief responses. Within the literature little has been written about how nurses make meaning of loss and death when delivering end of life care in acute settings and the steps they actually take to address this.

Health care professionals have their own accumulated values and beliefs around death and dying and histories of grief and bereavement and need to review their own biases and experiences of grief. Nurses should explore the concept of grief but also be aware that the phenomena of grief is a human process and they are people first. The evidence presented points to a strong focus on the requirements for active support for nurses ongoing wellbeing whatever form that may take. It has also been noted that it may serve to give reassurance to the bereaved that their experiences are shared by others including the nurses caring for the dying patient.

4.5.1 Rationale for the study

The Scottish Government published the Strategic Framework for Action on Palliative and End of Life Care which outlined key actions that would support the provision of palliative and end of life care for everyone in Scotland who needed it (Scottish Government. 2015). The outcome of this publication is a significant increase in demand for palliative and end of life care in acute settings, with no additional specialist palliative provision and inpatient, acute end of life care beds available to deliver the care required.

Policy often drives practice and although there is a recognition that the care needs for the population of Scotland are changing, palliative care continues

to form a significant part of the work of a generalist nurse working in an acute patient setting.

There is limited research in palliative care overall and no evidence found to understand the experience of delivering end of life care in acute settings for nurses, the impact on their practice and how they manage their own thoughts and emotions when faced with death and loss of their patients, while also supporting bereaved loved ones. Understanding this will give nurses a voice in what they need to support this unique experience.

The literature review sought to answer the research questions and the starting point of the review was the act of caring for the dying and the lived experience of the nurse delivering that care.

With the above in mind the overarching aim guiding the current research is to explore and understand the lived experience of professional grief that palliative care nurses in an acute setting experience whilst delivering end of life care and care after death. To achieve this aim three guiding research questions are :-

1.   What are the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying ?

2.   What is the palliative care nurse's response to the loss of a patient when working in acute settings?

3.   What is the meaning of loss and death experienced by palliative care nurses working in acute settings after the death of a patient ?

Evidence identified that nurses need to feel that they have contributed to the care of their patients which allows the patient to meet the social priority of experiencing a good death. Defining a good death however can be subjective and rely on the layers of emotions, thoughts, feelings and values of both the patient, family and the nurse themselves.

Several attributes of care and characteristics of the nurse were examined together with a review of grief theory and professional grief to identify any previous studies within the UK in general and Scotland in particular.

The question of professional grief of nurses in acute settings delivering palliative care has not been addresses in the literature. Other studies were

identified which had component parts which could contribute to this research. They identified that relationships are fundamental at end of life and spiritual care of the patient and nurses themselves, contributed to emotional wellbeing. The desire to care for others was often an inherent trait however the impact of emotional drain on the nurse should be considered.

A systematic scoping review of palliative and end of life care research in Scotland from 2006–2015 identified that whilst there had been a steady increase in palliative and end of life care research in Scotland there was a distinct lack of evidence and research around interventions for clinicians, carers and bereavement support (Finucane et al., 2018). There had been no studies conducted around the meaning of grief and loss for nurses delivering palliative and end of life care in acute settings. Research in this area would add to the body of knowledge around the subject and may impact on care delivery to improve the delivery and quality of end of life care whilst meeting the requirement of care and support of nurses working with people at end of life and the bereaved in the acute setting.

Chapter 5
Methodology

5.1   Introduction

This chapter explores the theoretical underpinning for the approach and method used for this study. It is important to consider the research question and aims and objectives of the study. The aim of this study is to explore and understand the lived experience of professional grief that palliative care nurses in an acute setting experience whilst delivering end of life care and care after death. To achieve this three guiding research questions were developed, as follows :-

1.   What are the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying ?

2.   What is the palliative care nurse's response to the loss of a patient when working in acute settings?

3.   What is the meaning of loss and death experienced by palliative care nurses working in acute settings after the death of a patient ?

Early in the development of ideas around this study a qualitative approach was identified as being most suitable. This chapter will give a background to that assertion and underpin the choice of approach. A definition of qualitative research will be given followed by a more in depth explanation of commonly used qualitative research methods, ethnography, grounded theory and IPA. The purpose of this chapter is to identify the most appropriate approach which takes into account the skills and values held by the researcher to achieve the aims of the study.

5.2   Nursing and qualitative research

The aim of nursing according to Kelly and Long (2000) is the delivery of high quality service based on reliable and valid research findings. To answer the question of which approach to follow, nurse researchers dichotomise and categorise research methods to arrive at one or other paradigms of

qualitative or quantitative. According to Kelly and Long (2000) historically the quantitative approach has been used with a perception of high status and logical positivism. Alternatively however Clark (1992) proposes that nurses do not find this approach comfortable or appropriate for the research topics central to their practice. Silverman (2000) adds that qualitative researchers can assume that reliance on purely quantitative research can often disregard the cultural and social aspects of the variables which quantitative research aims to correlate. This view is supported by Duffy (1985) who states that a positivistic approach is not possible when investigating the social world. Conversely critics of qualitative research view it as a soft option and inferior, lacking scientific rigour (Kelly & Long, 2000). Creswell (2007) suggests that procedures for conducting research are shaped by the researchers' theoretical and philosophical stances. Kelly and Long (2000) add that nursing studies using quantitative and qualitative approaches have previously been lacking in articulation regarding their philosophical underpinnings and therefore choose a methodology without clear appraisal of the philosophical issues and have little awareness of the implications of post-positivist philosophies for nursing research.

Following this approach, the researchers theoretical and philosophical stances were used to guide the selection of a qualitative methodology as this was perceived to be the most appropriate see Table 1. Furthermore an established approach to examining lived experience of a phenomena is needed to underpin the current research and avoid the previous ambiguity found in past nursing research.

5.3 Defining qualitative research

Gagliardi et al. (2014) describe qualitative research as deconstructing, describing, or interpreting the meaning given to a phenomena by groups and individuals. Their behaviour and contextual factors also affect how meaning is given. A range of approaches can be used such as interpretive, phenomenological and hermeneutics and there are a range of methods for data collection such as observation, interviews and focus groups. When phenomena are difficult to measure quantitatively then qualitative experimental methods can be very useful (Gagliardi et al., 2014).

Ball et al (2011) carried out a systematic search and bibliometric study of the application and design of qualitative methods in nursing research between 2008 and 2010. A total of 240 papers were analysed using a four step mixed methods approach. They found that 27% had no or ad hoc reference to qualitative terminology and methodological terms were used inconsistently, they concluded that qualitative was used as a catch all term and not a methodology with defined terms and contextual definition. Ball et al. (2011) describe the term qualitative as a logical grouping of related concepts which are used to highlight and bring together many aspects that are interdependent and complex in nature. Conversely they say however that this description could not be a true proposition as the structure, variation and sophistication of qualitative research can enable it to adapt to many environments and this in turn makes it suppositional as opposed to propositional (Ball et al., 2011).

Ball et al. (2011) suggest that qualitative research must be robust and able to stand alone and withstand scrutiny. There must be quality control measures that are relevant and within context such as rigour which should be a priority regarding citation of analysis or methods. Theoretical terms should be used consistently ensuring the rigour of the chosen methodology and finally the researcher should ensure that qualitative is not a *"catch all panacea"*.

According to Clifford (1997) reliability and validity have great emphasis in research in general. Reliability refers to consistency in measurement when using research tools such as questionnaires and great care must be taken to remove any extraneous variables which may impact or influence that which is measured. As participants are often asked to describe things in their own words in qualitative research questionnaires there is a likelihood that responses may be inconsistent and therefore reliability is often described as low compared to structured questionnaires used in quantitative research (Clifford. 1997). Conversely validity is often seen as high in qualitative research as the researcher can measure what is supposed to be measured with much greater ease. Validity can also be assessed by returning to the participant to check the interpretation of the data and if the interpretation is deemed to be inaccurate then procedures for analysis of the data can be reconsidered (Clifford. 1997).

According to Gagliardi et al. (2014) modern healthcare environments are complex by nature and the need for qualitative research to inform quality improvement and evaluation is necessary in many circumstances. Ball et al. (2011) highlight the natural coalescence between qualitative research and nursing and the resulting application of theory to practice which results in the methodology being used to answer nursing questions, many of which are based around phenomena grounded in patient experience. Qualitative research also allows the researcher to link into and with the context, culture and practice environment which is important in understanding the complex nature of nursing care, particularly in an end of life care setting.

5.4   Qualitative research design

The research design is the plan used to decide how data will be collected and eventually analysed and determines the approach taken. A qualitative approach would allow the researcher to gather descriptive accounts of the phenomenon which are rich in nature. Qualitative research is an interactive approach between the researcher and the participants in the research study from which the researcher uses inductive reasoning to gain meaning from the situation or phenomena researched (Clifford. 1997).

 According to Creswell (2007) the design process in qualitative research begins with philosophical assumptions and researchers bring their own world view and beliefs to the research project. Philosophical assumptions impact on the choice of qualitative research and the assumptions include the ontological, epistemology, rhetorical, axiology and methodological assumptions (Creswell. 2007). Guba and Lincoln (1988) developed a table to illustrate the philosophical assumptions which lead to the choice of qualitative research (Table 1). Creswell (2007) believes that qualitative research is legitimate in its own right and does not require comparison to achieve acceptability or respectability. He describes ontological issues as relating to the nature of reality and that when qualitative research is conducted the researcher embraces the idea of multiple realities. The epistemological assumption means that researchers get close to the participants of the study and conduct their research in the field which allows important context to understand what the participants are saying. According

to Flood (2010) the epistemology of phenomenology focuses on revealing meaning as opposed to developing abstract theory. The axiological assumption is that researchers bring value to a study and make those values explicit and actively report their values and biases along with the nature of the information gathered (Creswell 2007). Further, Creswell (2007) asserts that qualitative researchers usually hold the rhetorical assumption that the writing should be personal, using metaphors such as "I" and qualitative terms such as "understanding", "discover," and "meaning" are used as opposed to quantitative terms such as "internal validity" and "objectivity" (Creswell. 2007). In conclusion Creswell (2007) states that the methodology of qualitative research is characterized by an emerging process which is shaped by the researchers experience in collecting the data and is an inductive process shaped by the ground up. Table 1. presents theoretical and philosophical stances which were used to guide the selection of a qualitative methodology from an initial starting point or " ground up" as described by Creswell (2007).

Assumption	Question	Characteristics	Implications for Practice
Ontological	What is the nature of reality?	Reality is subjective and multiple, as seen by participants in the study	Uses quotes and themes in words of participants and provides evidence of different perspectives
Epistemological	What is the relationship between researcher and researched?	Attempts to lessen distance between himself and that being researched	Collaborates, spends time in field with participant and becomes an insider.
Axiological	What is the role of values?	Acknowledges that research is value laden and that biases are present	Openly discusses values that shape the narrative and includes their own interpretation in conjunction with the interpretations of participants
Rhetorical	What is the language of research?	Writes in a literary, informal style using the personal voice and qualitative terms .	Uses an engaging style of narrative, may use first-person pronoun, and employs the language of qualitative research
Methodological	What is the process of research?	Uses inductive logic, studies the topic within its context, an emerging design	Works with details before generalization, describes in detail the context of the study, continually revises questions .

Table 1 Philosophical assumptions with implications for practice (Guba and Lincoln. 1988)

In addition to the philosophical assumptions Creswell (2007) notes that researchers further shape their approach through their understanding of world views which is action guided by a particular and basic set of beliefs.

The four views suggested by Creswell (2007) are firstly postpositivism which takes a scientific approach. It is logical and reductionist with the emphasis on empirical data collection which is deterministic and based on prior theories. It is a systematic approach with the results usually written in a form of scientific report resembling the approach of quantitative research. This approach is seen in phenomenology and grounded theory.

The second view is that of social constructivism which allows the researcher to seek understanding of the world in which they live and develop subjective meaning of things. The goal of the research is to rely on the participants' view of their own situation which is negotiated socially and formed through interaction with others. In contrast to postpositivism this stance allows the researcher to inductively develop a theory. This view is apparent in phenomenological and grounded theory studies (Creswell. 2007).

Thirdly an advocacy/participatory world view is used when predefined theories do not fit participants that are marginalized as in postpositivism and social constructivism does not offer processes to help participants. The view of the advocacy/participatory approach is that the research should contain an element of agenda for change which may impact the participants, the institutions in which they operate or the researcher themselves. The ethnographic approach is the most common used with this world view.

Pragmatism is the final world view discussed by Creswell (2007) in which the researcher focuses on the outcomes of the research and are not bound by any one system of philosophy or reality. They may in fact use multiple methods of data collection to enable them to answer the research question and employ both qualitative and quantitative methods. This world view is often seen in ethnography and case study researchers. Action research is one such methodology where the initial aim can be for participatory learning and development and therefore potential change.

Analysis of the four world views revealed that to explore and understand the lived experience of professional grief that palliative care nurses in an acute setting experience an appropriate view must be selected to underpin the research. The advocacy/participatory view which contains an element of agenda for change and the pragmatism view which focuses on the outcomes of the research and may use both qualitative and quantitative research methods and does not align with the research question. Ethnography is usually the approach taken for these two views. Only postpositivism, which is reductionist and based on prior theories and social construction, which allows the researcher to inductively develop a theory, fit the aims of the

research question. Phenomenology and grounded theory are usually the approaches taken for the two views.

5.5   Approaches to qualitative research

The three most common approaches to qualitative research according to Clifford (1997) are ethnography which is influenced by anthropological theories, grounded theory which is influenced by sociological theories and phenomenological analysis. All three approaches use inductive reasoning but differ in perspective depending on which particular orientation is used. An approach that represents the lived experience of the nurse is needed to fully answer the aims of the research question. The approaches will be presented discussed and evaluated to establish the most appropriate in order to fully answer the research question.

5.5.1 Ethnography

Ethnography is a theory of research that contains a number of characteristics or criteria. It is an iterative process which evolves throughout the research process (O'Reilly. 2009). It also involves a variety of methods to gather data to allow triangulation over a period of time (Sangasubana. 2011). It is a social science research method which relies on very close and personal experiences and participation as opposed to simple observation and has its roots in sociology and anthropology. It is also a means of gaining perspective on local points of view and identifying human experiences through engaging and being interactive with the participants. This method allows observation of sometimes subtle areas of difference, similarity and perception (Genzuk. 2003).

For ethnographers field work is the period of data collection that occurs whilst the researcher is in "the field". It can consist of gaining access to the participants or area of study, recruitment and establishing an insider role to assist the development of an emic perspective. Building rapport, ensuring an etic perspective is retained and avoiding "going native" (O'Reilly. 2009). Genzuk (2003) reminds us that there is no one set of rules for conducting fieldwork as it is situation dependant. The purpose of the study, type of

setting and the skills experience and views of the observer are all important in the approach taken. The general guidelines suggests however that field notes are very important and should be as descriptive as possible. Information can be gathered from a variety of different sources and perspectives which will allow the researcher to cross-validate and triangulate. He also urges the researcher to use quotations to allow the participants experiences to be captured in their own words. There are also different stages of fieldwork which consist of the initial stage of building trust and rapport. The middle stage of routine data collection, where the researcher must stay alert and disciplined. The drawing to a close of fieldwork where the researcher must focus on pulling together a useful synthesis of the work. Finally the researcher should provide formative feedback as part of the verification process of fieldwork which should be timed correctly and occur throughout the process and the researcher should observe the reaction to feedback to inform results further (Genzuk, 2003). They may be spoken and recorded using a tape recorder or written in a diary. The pages of the diary should be dated and timed and the site of the interview recorded together with the details of the participants of the interview. Finally the field notes should be cross referenced to the interview schedule to allow the researcher to keep track of data and related observations to each interview (Morse & Field. 1996).

The methodology of ethnography requires the researcher to first decide where to study and how to gain access to the participants and may require negotiation and renegotiation with different groups throughout the course of the research. Once introductions have been established however an explanation of the research and the reasons it is being carried out is very important. The information must be given in a clear format and in a context the participant can understand. It is good practice to provide a written account explaining the mode of research, reasons for carrying out the research and what the researcher aims to gain by conducting the research (O'Reilly. 2009). Once the participants have received a verbal and written explanation of the research to be carried out a reasonable amount of time is required for them to digest the information before giving formal written consent that they would like to be involved in the study.

The researcher must also choose which role they are going to assume throughout the research as this can affect how the participants see the researcher and influence how they act towards them and allow access to them (O'Reilly. 2009). People will find it much easier to relate to somebody they understand within the context of the research setting. If a researcher has had previous experience of the role they aim to research and observe the participants may feel they have more confidence in the researcher and be able to relate to them and so foster a more trusting mutual relationship. O'Reilly (2009) also warns the ethnographic researcher to give some thought to what will happen at the end of the research process and how they will disengage from the subjects. She warns against the lure of acceptance in the field and over rapport which could result in a lack of objectivity. A phenomena known as "going native" is explained by Ditton (1977) as "getting a case of the Pyles's" which refers to a researcher named Pyles who had a yearning to stay on after his research had concluded and was influenced by the pleas of his participants for him to stay and help with the labour shortage throughout the summer. The researcher felt the" lure of acceptance" and wanted to remain part of the group (Ditton. 1977). The position the ethnographer takes is somewhere between empathy and distance, taking both the emic and etic approach. This can become uncomfortable for the researcher as they strive for acceptance.

Observational methods are used to capture the data and these can take the form of participant observation which in turn is made up of many characteristics. It can combine document analysis, interviews, participation, observation and introspection. The researcher intimately shares in the activities of the participants in the observed setting. In this way an insider's view of what is happening is achieved and the researcher not only sees but also feels what it is like to be part of the group (Genzuk. 2003).

Interviews do not need to be formal and pre-arranged and develop out of opportunistic conversations which consist of questions and answers. The context in which the conversation is held is also important and the searcher must pay attention to this noting how the information is exchanged, to whom, when and where. Also what is not said can be equally important. This perspective is often gained through long term participant observation not

through direct interviewing (O'Reilly. 2009). If formal interviews however are to be conducted then the researcher must ensure that they keep centred on the purpose of the research endeavour and let that endeavour guide the interview Initially however it would be useful to provide a framework which will allow the participant to express their own understanding in their own words.

Focus groups can also be a good source of data and differ from interviews in so much that interviews can imply power relationships with images such as job interviews or defending ones views whereas focus groups can be directed towards a group discussion. The group discussions can become very creative and dynamic allowing shared meanings and understandings (O'Reilly. 2009). Interviews and focus group discussion should be recorded and transcribed as soon after the event as possible together with field notes to ensure accuracy of data, inflection and connotation of the participant and researcher.

Once the research has been completed and the data recorded then the task of analysis, interpreting and reporting of the findings can begin. Initially the data is analysed through gathering the raw materials to gain an overview of the entire process. All sources of data are considered such as non-verbal signs, tone, context, frequency, extensiveness, intensity and specificity. This data is then brought together to bring order to it by identifying patterns, categories and descriptive units. Data reduction strategies are used to refine the parameters. Interpretation of the refined parameters is then able to take place and this takes the form of attaching meaning and significance to the analysis. Descriptive patterns are explained and relationships and linkages identified (Genzuk. 2003). These methods can be used in both ethnography and phenomenology.

Genzuk (2003) states that as observational research is not a single thing and using field methods to collect data is only the first step in deciding which methodology to use. To gain an insider's view of what is happening requires the researcher to become part of the group and to share as much as possible in the activities of the people in the shared setting. This ensures the researcher not only sees what is happening but understands how it feels to

be part of the group. Ethnographic research fits with the researches style of learning and the subject matter to be researched as ethnography allows strategies of investigation which reveal the world view of those being researched as a total phenomenon.

5.5.2 Discussion around use of ethnography for this study

It is important to understand the context, setting and practices of the nurse within this study and ethnography does not allow for close examination of the lived experience of the research participant. The ethnographic researcher becomes part of the group and may strive for acceptance. This could result in building close rapport with the participants and result in a lack of objectivity as it is very difficult to navigate a position between empathy and distance. If a close intimacy with the participants is established then the researchers perspective can change subtly to that of a fellow participant with an insiders point of view leading to an unconscious bias. This methodology therefore was assessed as being unsuitable for the study.

5.5.3 Grounded Theory

Grounded theory was developed in sociology and is a method used to gather synthesize and analyse qualitative data and can be used to construct theory. Glaser and Strauss (1965) developed the methodology to address their perceived failures of other methods as they found the other methods available did not meet their requirements. They believed that theories should be "grounded" in data. The development of grounded theory allowed actions and interactions to be analysed through inter-relating categories gathered from data which was collected from individuals (Creswell. 2007). According to Creswell (2007) the intent of grounded theory is to generate a theory and move beyond description. Silverman (2000) suggests the purpose of grounded theory is one of theory construction rather than the application of existing theories. Through a collective experience of the process by the participants, a theory can be developed which helps explain the practice and may provide a framework for further research and inquiry (Creswell. 2007). The data is simultaneously collected and analysed which allows for creation of abstract conceptual categories derived from an explanation of the data

(Charmaz & Bryant. 2011). The literature review is often not undertaken until the analysis has been carried out which ensures that analytic codes and categories are developed from the data and not from a preconceived hypothesis. Silverman (2000) highlights the criticism that grounded theory has attracted due to its failure to acknowledge implicit theories used as a guide during the early stages of research. He further argues that if not carried out correctly and to a high standard it can become a list of categories to legitimise purely empiricist research.

Grounded theory however can incorporate both positivistic and interpretive approaches and aspects of it can be used with an ethnographic approach. Charmaz and Bryant (2011) describes how grounded theory ethnographers move from attempting to capture everything about a particular subject to focusing on one particular area to explore or observe through following leads to develop their emerging theoretical categories.

Charmaz and Bryant (2011) in their discussion of the credibility of grounded theory suggest that there are issues around the method which attract criticisms. They are that the notion that researchers discover truth rather than create it and concepts emerge from the data, with the researcher acting in a passive way is farfetched and unlikely. They argue however that the view of the researcher as passive is accentuated through the idea that grounded research takes place in a vacuum due to the fact that researchers are encouraged to not engage with the literature and formulate research questions prior to carrying out the research. They argue that this approach allows development of an inductively achieved grounded theory about a particular phenomenon. They go on to suggest that the strategies used in grounded theory are flexible and are able to be used in contemporary qualitative inquiry and that methodological misunderstandings have undermined a popular and innovative method.

5.5.4 Discussion around use of grounded theory for this study

The aim of this research is not to develop theory but rather to examine the lived experience of the nurse and not to construct theory. Grounded theory

does not allow for acknowledgement of implicit theories which are crucial during the early stages of developing the aims of the research. The concept that the literature review should be undertaken after the data has been collected further adds to the potential for not clearly articulating or defining the research question. Theories of grief and professional grief were examined and used to inform the research to achieve the stated aims, which did not specify developing a new theory for professional grief. Grounded Theory would have been appropriate if this was the intention. Furthermore the gap in the literature or lack of current research cannot be clearly identified before the study is undertaken. The passive approach of the researcher does not underpin the close relationship to the participant and the data which is necessary to examine the lived experience of the palliative care nurse delivering end of life care in an acute setting. This methodology was also assessed to be unsuitable for the study.

5.5.5 Phenomenology

Phenomenology emerged from philosophical work of Hegel, Brantano and Kant according to Matua and Van Der Wal (2015) which influenced Husserl and inspired him to develop phenomenology. Heidegger, Merleau-Ponty and Satre were also important contributors to the thinking and development of phenomenology (Heidegger, 1962; Merleau-Ponty, 1962; Sartre 1956). Each took the concept into a diverse path however they maintained the core philosophy (Smith et al., 2009). Furthermore they assert that the core principle of phenomenology is that we should examine experience in the way in which it happens and under its own terms (Smith et al, 2009). This notion was first forwarded by Husserl (1965) who believed that if one could find a means to succinctly understand their own experience of a situation with depth and rigour then the essential qualities of that experience may become known to them. In this way the essential qualities of the experience would "*transcend*" their individual circumstances and could be used as an *"illumination"* for particular experiences of others (Smith et al., 2009). Heidegger was a student of Husserl and used Husserl's foundation of phenomenological enquiry to further develop his own thinking in the field. Heidegger (Heidegger. 1962) emphasised the move away from the

transcendental approach of Husserl to the hermeneutic and existential approach to philosophy proposing that knowledge should be grounded in an interpretive stance within the "*lived world*" which consisted of people, things, relationships and language. This brings into focus the *meaning* attached to phenomenological analysis and is more concerned with the ontological question of existence and the framework of activities and relationships through which the world becomes visible (Smith et al., 2009). Merleau-Ponty (1962) echoed Heidegger's view that we should have a more contextualized phenomenology. In contrast to the idea that we should frame phenomenology in the lived world, Merleau-Ponty suggests that we should examine our embodied relationship with the world as we see ourselves different from everything else in the world. We have a holistic sense of self which allows us to engage with the world rather than being merely placed within it (Smith et al., 2009). Finally Sartre (1956) further develops the views of other phenomenologist and suggests that although we possess a self-consciousness and strive to make meaning we enact a process of development which engages with the world in which we live. He poses that we are constantly striving to become ourselves and that the self is not one entity to be uncovered but an ongoing transformation or project to be discovered (Smith et al., 2009).

 Phenomenology has become a credible methodology for studying consciousness and in nursing in particular and is also a method of enquiry which aims to examine and explore and eventually understand the participants' everyday experiences. Moran (2000) describes phenomenology as anti-traditional and attempting to understand the truth. Creswell (2007) discusses four philosophical perspectives in phenomenology which are, a return to the traditional tasks of philosophy which is the Greek ideal that philosophy is a search for wisdom and a philosophy without presupposition in so much that all judgements about what is real are suspended until established on a more certain foundation. The third perspective is that consciousness is always directed towards an object and the reality of that object is related to ones consciousness of it. The dual Cartesian nature describing two different things that interact with each other describes both subjects and objects as they appear in consciousness. The final perspective

is that of the refusal of the subject-object dichotomy which relates back to the intentionality of consciousness. Perception of reality of an object is only realised within the experience of an individual.

5.5.6 Discussion around use of phenomenology for this study

Phenomenology aims to clarify situations experienced and lived by people in everyday life (Giorgi & Giorgi. 2003). The way in which the phenomena is experienced within context is sought from participants with first hand experiences allowing them to describe actual events. The researcher then attempts to analyse the responses to understand the psychological essence of the phenomena (Giorgi & Giorgi. 2003). An analysis of the meanings being lived by participants from a psychological perspective can be illuminating and revealing in nature (Giorgi & Giorgi. 2003). This is due to the fact that participants experience events and respond to situations in various ways but do not on the whole know how or why they respond in a certain way. Moran (2000) however had previously described phenomenology as a radical, anti-traditional style of philosophising. He goes on to state that it is an attempt to get to the truth of the matter and we must not impose our own explanations on the phenomena before they have been understood from within. Matua and Van Der Wal (2015) develop this idea by describing the start of phenomenological enquiry as the search for the nature of the meaning of the phenomena and seeks to explore the phenomena from the perspective of those experiencing it first-hand. They suggest that nurse researchers can use phenomenology to examine meaningful experiences of participants which therefore allows the nurse researcher to critically examine lived experiences that may be taken for granted and reveal hidden aspects or meanings. These hidden aspects can then be used by others in the same situation (Matua & Van Der Wal., 2015).

It would appear based on the above discussion that phenomenology is the best fit for this particular study but to ensure this decision was framed within a logical decision making process, further tools were used to confirm the decision. The following section will discuss and demonstrate the decision

making process to select phenomenology using a S.W.O.T analysis and a Matrix tool.

5.6 Identifying the study method

The preceding sections of this chapter have thus far described three main approaches adopted in qualitative research, highlighting the philosophical underpinnings, aims, and process which are adopted using theses differing approaches. Phenomenology appeared to fit the study aims but to ensure a reduced risk of bias, a further analysis of these approaches was undertaken through the use of a S.W.O.T. analysis (Table 2). This was used to illustrate strengths, weaknesses, opportunities and threats of using phenomenology, ethnography and grounded theory approach in relation to the research question. The use of the S.W.O.T analysis allowed structure and gave definition to the choice of methodology. A Matrix analysis (Figure 6) was a further tool used to add clarity and measure the impact of the chosen methodology against achieving the aims of the research. Through the use of these two tools the choice of methodology was placed within a framework to ensure clarity of approach and aims were achieved.

5.6.1 Rationale for choice of methodology

5.6.1.1 SWOT analysis

In order to review the chosen methodology and frame it within a structure to identify risks and benefits of each methodology, a SWOT analysis was used. SWOT analysis is an acronym and predominantly used in the business field to identify an organizations strengths and opportunities and pinpointing its weaknesses and threats allowing effective strategies to be made for future trading (Humphrey. 2005). In this instance the tool will be used to identify and mitigate areas of risk within the choice of ethnographic, grounded theory and phenomenological research.

Awareness of opportunities and weaknesses within the chosen methodologies will be highlighted. It will ensure that processes happen in the correct order and therefore be in the position to add or remove steps as required. In this way the decision to use a particular research methodology

will be considered from as many different angles as possible. Analysis of the chosen methodology should lead to strong conclusions and good decision making. The process involves making an honest and realistic list under the four headings of Strengths, Weaknesses, Opportunities and Threats. This process may reveal valuable facts and insight in areas that could have been previously overlooked .

After analysis of the S.W.O.T diagram the phenomenological methodology ranked higher as it was more closely aligned to the objectives of the research, fits the epistemological and world views of the researcher and also the two weaknesses identified could also be viewed as opportunities.

Both the weaknesses of phenomenology could also be seen as strengths such as the researcher's subjectivity which may be used to inform analysis of the data and retrospective descriptions which may contain errors but also more accurately reflect the way situations were experienced or perceived.

The strengths of ethnography did not fit with the objectives of the research question as closely as phenomenology. However by using ethnography the researcher could identify local points of view and gain insight into subtle areas of difference and similarity. A threat of ethnography is that the position the ethnographer takes is somewhere between empathy and distance, taking both the emic and etic approach. This can become uncomfortable for the researcher as they strive for acceptance

Grounded theory gave the researcher the opportunity to discover truth rather than create it as concepts emerge from the data, this could also be seen as a threat. However as one of the weaknesses of grounded theory is that there is a failure to acknowledge implicit theories used as a guide during the early stages of research. A further weakness of grounded research is that if it is not carried out correctly and to a high standard it can become a list of categories to legitimise purely empiricist research. See Table 2.

S.W.O.T. Analysis

Strengths

Phenomenology	- It has become a credible methodology for studying consciousness and in nursing in particular. - Analysis of the meanings being lived by participants from a psychological perspective can be illuminating and revealing in nature. - Hermeneutic - which allows the researcher to examine meanings and experiences related to nursing research covering topics such as death.
Ethnography	- Reflect the personal growth and experience of the researcher. - Researcher not only sees what is happening but understands how it feels to be part of the group. - Identify local points of view and gain insight into sometimes subtle areas of human difference and similarity.
Grounded Theory	Researchers discover truth rather than create it and concepts emerge from the data

Weaknesses

Phenomenology	- A concern is that of the researcher's subjectivity but this may also be seen as an opportunity as it may add greater depth. - Retrospective descriptions - may contain errors either intentionally or unintentionally. This however could be viewed positively as the researcher is concerned with the way situations were experienced or perceived.
Ethnography	- Lure of acceptance in the field and over rapport which could result in a lack of objectivity. - Sometimes difficulty at the start of the research process to identify what aspects of the observations will be relevant to the developing analysis.
Grounded Theory	- Failure to acknowledge implicit theories used as a guide during the early stages of research. - If not carried out correctly and to a high standard it can become a list of categories to legitimise purely empiricist research.

Opportunities

Phenomenology	• A radical, anti-traditional style of philosophising. • Nurse researchers can use phenomenology to examine meaningful experiences of participants which therefore allows the nurse researcher to critically examine lived experiences that may be taken for granted and reveal hidden aspects or meanings.
Ethnography	• Involves a variety of methods to gather data to allow triangulation over a period of time. • All sources of data are considered such as non-verbal signs, tone, context, frequency, extensiveness, intensity and specificity. • Researcher would benefit through having knowledge of the nursing role within palliative care.
Grounded Theory	• The data is simultaneously collected and analysed which allows for creation of abstract conceptual categories derived from an explanation of the data

Threats

Phenomenology	• We must attempt to get to the truth of the matter and we must not impose our own explanations on the phenomena before they have been understood from within. • Novice researchers should be aware of major implications regarding the different methodologies.
Ethnography	• If formal interviews are to be conducted then the researcher must ensure that they keep centred on the purpose of the research endeavour. • The position the ethnographer takes is somewhere between empathy and distance, taking both the emic and etic approach. This can become uncomfortable for the researcher as they strive for acceptance.
Grounded Theory	• The researcher acts in a passive way • Methodological misunderstandings have undermined a popular and innovative method.

Table 2 SWOT analysis of research methods (Finnan 2015)

5.6.1.2 Matrix analysis

A further tool which was used to visualise and plot the various methodologies against set criteria was a matrix, through this tool the researcher was able to relate one criteria to another. The objective of the research was stated and then an X and Y axis used to state degree of criteria. In the example shown the criteria used were alignment to research objective and analysis of lived experience. The matrix analysis used two axis to plot the alignment of the three methods for discussion. The X axis plotted analysis of lived experience and the Y axis plotted alignment to research objectives. The three methodologies were then plotted across the matrix. See figure 6.The objective of the research was to understand through personal insight and experience how palliative care nurses make meaning of loss and death throughout the delivery of end of life care in an acute setting. Grounded theory showed the least alignment to the criteria specified and phenomenology with the greatest alignment. Using the guidance and analysis of the S.W.O.T tool the decision was reaffirmed that phenomenology was the best fit.   To this end further discussion is presented to underpin the selection of phenomenology as the chosen methodology.
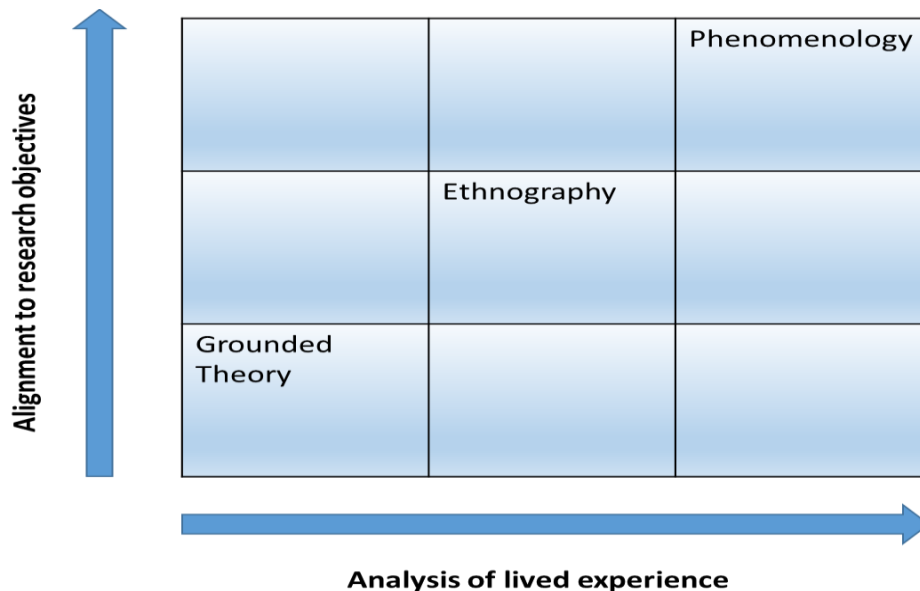
Figure 6 Qualitative research matrix

5.7. Further discussion on the application of phenomenology as a research approach

Phenomenology has transitioned from description as developed by Husserl to Interpretive developed by Heidegger (1962). The two approaches share the same epistemological foundation but have significant methodological differences and according to Matua and Van Der Wal (2015) novice researchers should be aware of major implications regarding the different methodologies.

Matua and Van Der Wal (2015) describe descriptive phenomenology as requiring researchers to seek the content of consciousness as close to the truth as possible and avoiding any preconceptions - a state they term *"phenomenological epoche or bracketing".* This describes the researcher's ability to ignore all existing knowledge of a particular phenomenon and so allows them to understand the essential elements which enables a direct contact as it is lived rather than conceptualised resulting in presupposition-less description of the particular phenomena. Moran (2001) suggests that a concern is that of the researcher's subjectivity which may influence or impact on the researchers view. Merleau-Ponty (1962) describes subjectivity as a perception of others coming from one's own embodied perspective and therefore connection and understanding of others begins from a position of difference. Bracketing or the process of "putting to one side" philosophical, cultural, and everyday assumptions in order to keep an open mind and not have any preconceived scientific or philosophical hypotheses can be seen as key to ensuring accurate data is collected. Moran (2001) describes how Husserl, the founder of phenomenology purports that in order to gain insight into the processes involved then the researcher must first suspend their natural attitude which would exclude distortion of the processes.

Husserl (1965) sees these characteristics as being central to the understanding and practice of phenomenology. This issue of subjectivity is not unique to phenomenology any may be experienced in other methodologies however it is in contrast to ethnography which requires full participation and experiences of the researcher to produce and analyse data (Moran. 2001).

Heidegger (1962) however argued that descriptions are already an interpretation as understanding underpins our "being in the world" and people usually find meaning in the events throughout their life which affects how these individuals operate. Therefore interpretive phenomenology incorporates pre-understandings which are not bracketed but incorporated into the research and may make the research and findings more meaningful (Matua and Van Der Wal. 2015).

Smith et al. (2009) highlights Heidegger's original idea that we are human beings who are part of a world filled with relationships, objects and language and that being part of the world is always in relation to those other things. In this way the theory of hermeneutics which concerns the interpretation of written texts meets phenomenology and the supposition by Heidegger that interpretation of something or some phenomena is founded upon fore-conceptions and is never pre-suppositionless. Heidegger cautions however that we must not allow popular conceptions to present fore-conceptions and Smith et al (2009) warns that priority should be given to the new object rather than the researcher's preconceptions when examining a particular phenomenon.

According to Dowling (2007) when phenomenological research is interpretive in focus and method then it becomes hermeneutic which allows the researcher to examine meanings and experiences related to nursing research covering topics such as death, life and pain. Interpretive phenomenology enables the researcher to interpret the meaning of the phenomena which produces a clearer understanding of what was intended to portray along with emphasising *"meaning of the meaning of the text"* or the psychological aspect of the text, speech or words in a particular context (Matua and Van Der Wal. 2015).

One concern may be the use of retrospective descriptions which may contain errors either intentionally or unintentionally. This however could be viewed positively as the researcher is concerned with the way situations were experienced or remembered by the participant and the account, although not exactly aligned to actual events, represents the participant's view of the experience (Smith et al., 2009).

5.7.1. Data collection for phenomenological research

The data could be collected through open-ended questions forming semi-structured interviews.Recording of the interview with consent can be carried out and transcribed at a later date. Field notes would assist in contextualising the data. Textual analysis is then undertaken and interpreted so one can understand the true meaning. We can categorise responses and identify relationships between them. Qualitative results are often expressed verbally which allow for a clearer understanding of interrelationships or complex situations. The process of recording the interview, transcribing the results and incorporating field notes allows for a triangulation of data to provide rich and thick data to inform the findings and discussion

5.7.2. Data analysis for phenomenological research

Colaizzi (1978) developed a method of analysis for phenomenological studies which entailed seven steps. The first step required the researcher to read the description of the participant's experience of the phenomenon to gain a sense of them. The second step required extraction of significant statements which show demonstrable connection to the phenomenon researched. The third step then entails careful analysis of the extracted statements to allow the researcher to formulate the meaning of each statement which requires the researcher to interpret the participant's meanings and therefore results in the formation of second degree themes or constructs. The fourth step involves organizing the themes into groups of related themes. In the fifth step the groups of themes are referred back to the original descriptions to allow validation and ascertain if there is anything included in the original description not included in the groups of themes and if the themes imply anything not implied in the description originally. The results of the group themes are then integrated into a description of the phenomenon researched in step six and step seven is the achievement of final validation through revisiting the topic of the phenomenon with the participant and ascertaining if the groups of themes compare with their experiences of the phenomenon which also allows the researcher to incorporate any new data into the description of the phenomenon. (Figure 7).
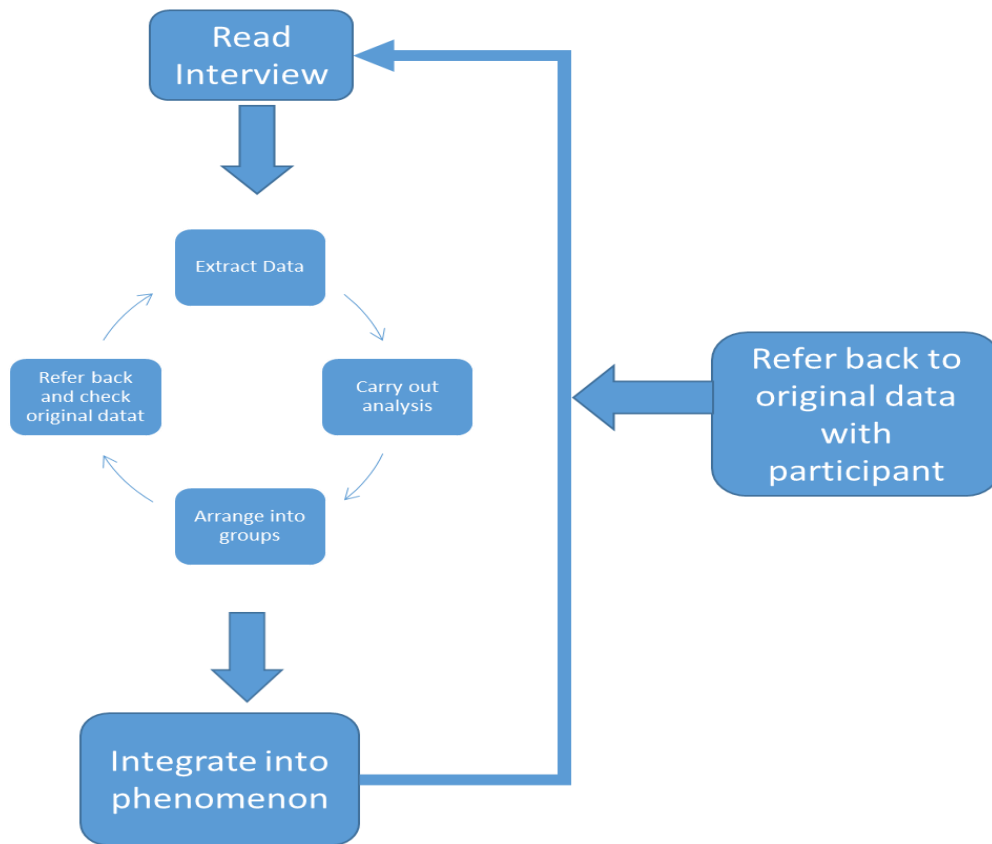
Figure 7 Method of analysis for phenomenological studies (Colaizzi 1978)

5.8. The development of Interpretive Phenomenological Analysis

Building on the tenants of phenomenology, interpretative phenomenological analysis (IPA) was developed by Smith et al. (2009). It has its base in psychology however it is increasingly being used in other disciplines such a social, human and health sciences. It is qualitative research approach used to examine how participants make meaning and sense of their life experiences. Smith et al. (2009) describe the IPA researcher as open-minded with patience, flexibility and empathy. They must also be willing to enter the world of the participant and respond to the participant within the context of their world. It is based on the suggestion of Husserl (1965) that we should go "back to the things themselves" and differs from other analysis styles as its aim is to interpret the meaning of the content of the participant's account of a particular phenomenon rather than fix experiences of the

participant into predefined categories. This approach is in contrast to other approaches such as those used by Colaizzi (1978) which whilst allow for analysis do not give the same depth. IPA is an analytical process that does not prescribe to a single method of analysis but rather supports the idea that IPA is analytical in focus (Smith et al., 2009). It does however have a set of common processes and principles which can be applied according to the parameters of the analysis and is an iterative process drawing on several strategies (Smith. 2007) .

The strategies that Smith et al. (2009) suggest are that analysis should be carried out closely line by line of the experience and understandings of the participant. Patterns are emergent and can be identified through emergence and divergence or commonality or difference and usually single cases are analysed first before identifying across subsequent multiple cases. There is a connection and interdependence between the researcher, the researchers data and their inherent knowledge. This creates a dialogue around what the participant feels and how they make meaning of a particular phenomenon within the particular context. This in turn leads to a development of an account which is more interpretative in nature. A gestalt or frame is developed to illustrate the connection between themes previously identified. The material which results from the analysis is organised which allows traceability back through the data from initial comments to structured themes. The use of audit, collaboration or supervision is paramount in ensuring quality and plausibility of the resulting analysis which should also be coherent. A full narrative can then be produced which shows evidence of data extracts, allowing the reader to travel through the researchers interpretation of the data in a theme by theme manner. This journey is often accompanied by a visual guide such as a diagram or table highlighting the salient points. Finally there is also evidence of the researchers own conceptions and perceptions of the data. Following this description of the strategies Smith et al. (2009) remind us that there is a great deal of flexibility and room for manoeuvre as the route through the strategies is not linear and is unique to each researcher and data.

The process of carrying out analysis within IPA encourage a reflective approach and engagement with the participant and the data and therefore

the analysis is a combination of input of the researcher and the participant. This process leads to a double hermeneutic approach as whilst the main aim of IPA is to understand the lived experience of the participant and the meaning they make of that experience, ultimately the results depend on how the researcher interprets those results or in other words how the researcher thinks the participant is thinking (Smith et al., 2009).

The initial step of analysis involves **reading and re-reading** the written transcript and by so doing immersing oneself in the data and **listening** to the recorded interview is also advised. The participant becomes the focus of the analysis in this way. The second step is to **examine somatic content** and note anything of interest in one margin. These comments fall into three categories of descriptive where the focus is on describing what the participant has said, linguistic which explores specific language used and conceptual which involves the researcher engaging with the text on a more conceptual and interrogative level. The third step is to **use the annotated text which will have** expanded the data which is used as the focus for developing emergent themes. The researcher then tries to reduce the volume of detail but maintain the complexity and interrelationships of the data through working primarily with the annotated notes in the margin whilst breaking down the original whole interview into discreet parts to work on separately. The interview becomes whole again once the analysis has been completed at the end of the process. Step four involves the **mapping of the chronological themes** already deduced but not all themes need to be used at this stage of the analysis. The scope of the research question may guide the inclusion of certain themes and discard others. A connection is then looked for between emergent themes. Step six involves moving on to the next transcript and repeating the processes already described but care must be taken to view the transcript in its own right and ensuring ideas gleaned from the first transcript are bracketed. Step seven then pulls all the cases together to look for patterns across the transcripts and deeper levels of interpretation can then be carried out (Smith et al., 2009). (Figure 8) .
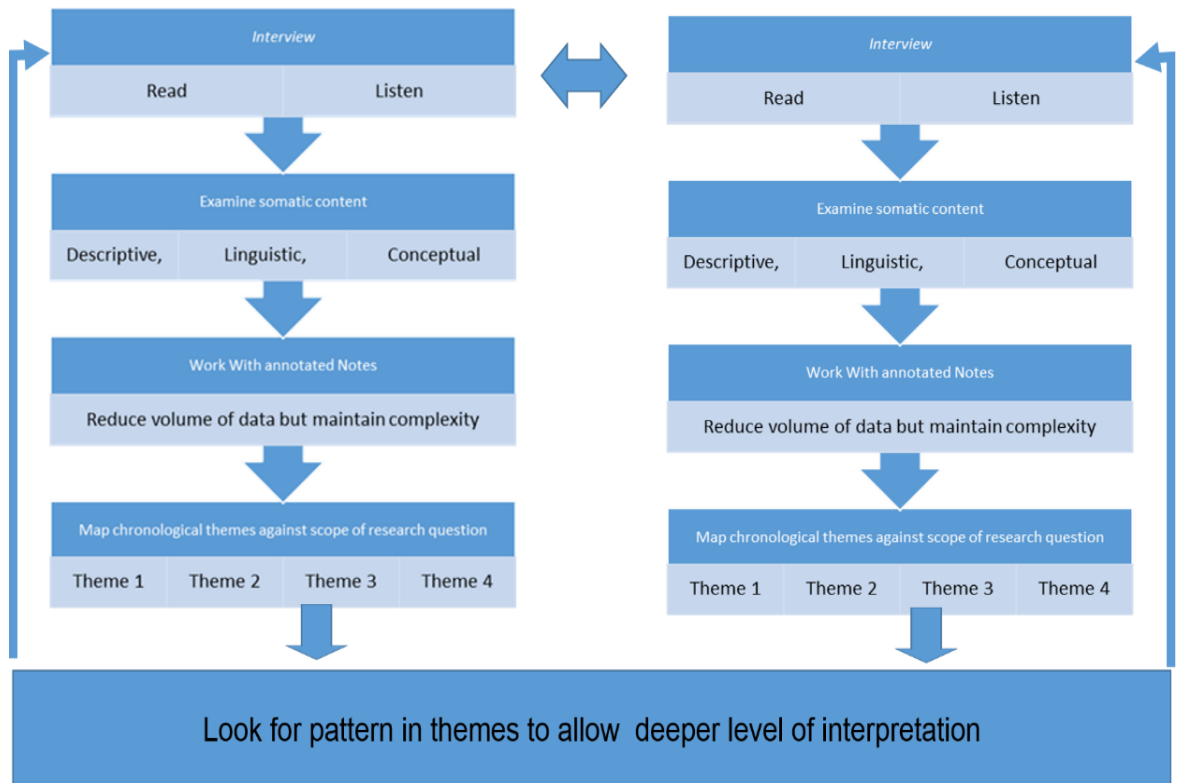
Figure 8 Proposed alternative method of phenomenological analysis according to Smith et al (2009)

Further to the assertion that phenomenology is the best methodological choice for this study from the above review it would appear that IPA would be appropriate for examining the lived experience of a participant within the current research. The process would enable the researcher to identify meaningful experiences of participants which could be critically examined further to reveal hidden aspects and meanings. The process of carrying out analysis within IPA encourage a reflective approach and engagement with the participant and the data and therefore the analysis is a combination of input of the researcher and the participant. This process leads to a double hermeneutic approach as whilst the main aim of IPA is to understand the lived experience of the participant and the meaning they make of that experience, ultimately the results depend on how the researcher interprets those results or in other words how the researcher thinks the participant is thinking (Smith et al 2009).These approaches moderate the perception of threat and turn them into strengths.

5.9. Chapter summary

The nature of the subject and the design of the research question necessitated a methodology which allowed the researcher to gain a clear picture of the nature of social reality and the phenomena of grief experienced by palliative care nurses delivering end of life care in an acute setting. Qualitative approaches derived from interpretative traditions appears the best fit for this type of research according to Kelly and long (2000). Smith et al. (2009) however caution against assuming a chosen method will have "stand alone integrity" and is not a pre-cursor of high quality research, rather the researcher must be creative in applying the techniques of a chosen methodology. They go on to advise that researchers must be organized, flexible and sensitive when collecting data and display systematic application of ideas and apply methodological rigour to analysis of data ensuring a combination of imagination and reflective and critical conceptual application.

The body of thought in hermeneutics originally sought to understand the interpretation of biblical text but developed to philosophically underpin the interpretation of a much wider breadth of texts such as literary and historical documents. The theorists of hermeneutics try to establish what the intentions of the original meanings of the author were and how the context of the text within its historical production relates to the interpretation of the text in the present day (Smith et al., 2009). Smith goes on to state that there is a connection and interdependence between the researcher, their data and their inherent knowledge. This creates a dialogue around what the participant feels and how they make meaning of a particular phenomenon within the particular context which leads to a development of an account which is more interpretative in nature. The process of carrying out analysis within IPA encourage a reflective approach and engagement with the participant and the data and therefore the analysis is a combination of input of the researcher and the participant. This process leads to a double hermeneutic approach as whilst the main aim of IPA is to understand the lived experience of the participant and the meaning they make of that experience. Ultimately the results depend on how the researcher interprets those results or in other words how the researcher thinks the participant is

thinking (Smith et al., 2009).These approaches moderate the perception of threat and turn them into strengths.

Following analysis of the philosophical assumptions and world views of the researcher of social constructivism a phenomenological approach was deemed to be the best fit. However ethnography and grounded theory were also explored in order to compare and contrast differing methodologies. These were discounted as they did not fit the objectives of the research question. The SWOT analysis identified that phenomenology was a credible methodology to use in studying consciousness in nursing which allowed analysis of the meaning being lived by participants in the study.

The matrix analysis used two axis to plot the alignment of the three methods for discussion. The X axis plots analysis of lived experience and the Y axis plots alignment to research objectives. Grounded theory showed the least alignment to the criteria specified and phenomenology with the greatest alignment. Through the use of analytical approaches described above, IPA was identified as the methodology which aligned most consistently to the research aims and objectives and therefore was selected to frame the research carried out.

Chapter 6
Research design and methods

6.1 Introduction

The overall aim of this study is to explore the lived experiences of professional grief that palliative care nurses experience whilst delivering end of life care and care after death in acute settings. The objectives are to :

a. identify the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying.

b. Understand their response and how they make meaning of that loss and death.

Palliative care nurses need to be compassionate but remain within professional boundaries which can be very difficult when working closely with patients and their loved ones. Chapter 2 and 3 concluded that actions and decisions taken in a personal relationship are usually based on emotions as opposed to knowledge with cognition forming the basis for professional decisions. Nurses must however realise and accept that they personally and collectively also need care (Tschudin. 1997).

The Living and Dying Well report highlighted that care and support for staff who care for the dying and deceased should be a concern of health boards who employ them (Scottish Government. 2011).

Through research the needs of the palliative care nurse can be identified and understood. In the research methods chapter, the SWOT and matrix analysis identified that phenomenology was a credible methodology to use in studying consciousness in nursing which allowed analysis of the meaning being lived by participants in the study. The process of carrying out analysis within IPA in particular encourages a reflective approach and engagement with the participant and the data. Therefore the analysis is a combination of input of the researcher and the participant.

6.2   Ethical approval

According to Polit and Hungler (1995) one of the essential elements of ethical principles is that of beneficence in which the researcher endeavours to "above all, do no harm". They go on to suggest that although exposing participants to serious or permanent harm is unacceptable the researcher should not refrain from asking questions about weaknesses, fears or personal views but should analyse the nature of intrusion on their participants. Questions should be asked in a sensitive manner and phrased tactfully.

Due to the nature of this research and the qualitative approach care was taken in carrying out the research as personal involvement and close relationships could develop between the participants and the researcher which could generate ethical and personal difficulties. Ryen (2011) advises that a good rapport can lead to participants to disclose emotional experiences but questions if this in itself is harmful to the participant. The physical, emotional and psychological wellbeing of the participants must be considered as probing questions exploring the feelings of the participants may impact on them negatively. The researcher must be aware of this and know when to stop asking questions or change direction according to Field et al. (2001) and this was acknowledged throughout the study. The researcher must know how to take appropriate action to reduce stress and prevent harm for the participants.

A further element of ethical principles is that of respect for human dignity which encompasses the right to full disclosure and self-determination (Polit et al., 2001). Informed consent ensures that the participant has clear and concise information regarding the study, that they understand the information and have free choice to participate voluntarily in the study.

The ethical considerations of this study ensured that an ethically acceptable informed consent form was distributed to all potential participants prior to commencement of the study. This was in accordance with the declaration of Helsinki which states that subjects must be volunteers and informed participants in the research project (World Medical Association 2013). The researcher must also ensure that the participant understands the information

and that they are informed of the nature, significance, implications and risks associated with the study. Consent obtained must be written, dated and signed and version control must be implemented if consent is superseded.

Polit et al. (2001) suggests a debriefing session should be carried out after the data collection phase has been completed and suggests participants may need referral to appropriate agencies for support. This was undertaken within this study.

Approval to undertake the study was given by the NHS Ethics committee, Borders Clinical Governance Department as part of the local NHS R&D processes and Edinburgh Napier University Research Integrity Committee. A full ethics application through the integrated research application system (IRAS) was not required as no patient data or participation was required for the study.

6.3   Sampling strategy

The target population is the total population of interest to the researcher and the study or accessible population is the segment of the target population from which the participants are chosen (Gerrish & Lathlean. 2015).

Polit et al. (2001) state that sampling entails selecting a segment of the population which is an aggregate of the entire population. The segment is also extracted from an accessible population but care must be taken to avoid sampling bias to ensure overrepresentation or under representation is not achieved.

Gerrish and Lathlean (2015) describe two categories of sampling design which are probability and non-probability sampling. Probability sampling is often used in quantitative research as the aim is to recruit a representative sample of the target population which allows bias to be quantified. Conversely qualitative research favours nonprobability sampling where the target of the research is on participants who can provide rich data from individual cases. Polit and Hungler (1995) suggest that nonprobability sampling is not as specific as probability sampling in producing representative and accurate samples but they go on to acknowledge that most research samples in many disciplines are nonprobability samples. The

three main methods of nonprobability sampling are convenience, quota and purposive.

Using participants for a study who are readily available denotes convenience sampling. The participants however may not be typical of the population to be studied and therefore bias may be created. Quota sampling incorporates a degree of knowledge about the chosen population to be researched and therefore allows the researcher to build some representativeness into the sampling plan. Quota sampling allows an enhancement of representation of a non-probability sample and is therefore an improvement over convenience sampling but still carries many of the same weaknesses. The most frequently used method for qualitative research is purposive sampling which is a method of selecting participants who are knowledgeable about the subject under study and assumes the researcher has knowledge about the population from which the participants are selected. A criticism of this method of sample selection could be that there is no external or objective method for assessing how representative the subject group is (Polit et al,. 2001). Smith (2003) however asserts that purposive sampling allows the researcher to find a more closely defined group which supports the aims of answering the research question. Smith et al. (2009) go on to say phenomenological researchers seek out homogenous sample groups who will find the research question meaningful. Furthermore he assets that a detailed account of the participants included can only be carried out if a very small sample size is used.

Polit et al. (2001) state that the criteria for sample size within qualitative research is not firmly established and should be based on information needs. They go on to suggest that phenomenological studies typically consist of ten or fewer participants. According to Smith et al. (2009) sampling should be purposively selected in order to conform to the theoretical approach of qualitative analysis in general but IPA's paradigm in particular. An idiographic approach is taken through recruitment of participants that grant perspective of a particular phenomenon, a detailed account of the experience can then be derived which reflects particular perspectives rather than populations. The sample size within phenomenology tends to be small with some researchers opting for single

case studies and the optimum number between six and ten (Smith et al., 2009). Guest et al. (2006) carried out analysis on a data from sixty in depth interviews carried out with women in two west African countries. They systematically documented the extent of data saturation throughout their thematic analysis . They made evidence based recommendations that data saturation occurred within twelve interviews, however elements for metathemes were identifiable after only six interviews were analysed. Greenstreet (2016) suggests that a study with a focused nature is more likely to support a small sample size and found that twelve participants were enough to discern themes concerning common views. Her study sought to explore nurses lived experience of spirituality as a means to cope with loss associated with terminal or chronic disease.

The sampling strategy undertaken therefore dictated that a purposive sample approach was taken. To this end the nurses were recruited from an acute palliative care ward. This approach ensured that they met the criteria of having experience of delivering end of life care and care after death within an acute setting to multiple patients. The breadth and depth of experience caring for the dying was imperative to the study and recruiting participants from an acute palliative care ward ensured this important criteria was met. The sample size was derived through availability of participants, with a total of ten nurses meeting the inclusion criteria within the team on the palliative care ward. This sample size was compatible with the nature of phenomenological study which relies on quality not quantity due to the complexity of phenomena examined, resulting in a concentration on a small number of participants (Smith et al., 2009).

A total of seven participants were recruited and this figure was in line with the assertions of previous researchers undertaking similar studies examining lived experience of their participants using IPA methodology (Greenstreet, 2017;Polit et al,. 2001; Smith, 2007).

6.4 Inclusion/exclusion criteria

Only staff nurses working within the palliative care ward from day and night teams were approached to take part in the study. The Senior Charge Nurse

or health care support workers were not included as the study aimed to address the research question pertaining to staff nurses. Other clinicians within the ward would have different degrees of preparation for delivering end of life care, together with different roles and responsibilities. The palliative care ward within the acute hospital was selected as whilst end of life care is delivered on other wards within an acute hospital the level of expertise and number of deaths experienced by the team is unique to this area. This form of sampling could be described as convenience sampling as the participants are readily available however the specific characteristics and nursing role held as nurses on an acute palliative care ward denotes a system of purposive sampling. The number of participants for this study however was dictated by available participants and to this end all ten members of the palliative care nursing team working on the ward were contacted and invited to take part in the study. Seven members of the team agreed to take part in the research. Only ward based palliative care nurses who form part of the team who have agreed to take part in the study were included. Nurses who were not ward based palliative care nurses or had declined to give consent were not included in the study.

6.5   Participant recruitment

Participants should be accessible, willing to provide information and illuminate a particular phenomenon being explored according to Creswell (2007). A purposive sampling approach was used selecting a small group of homogenous participants from an acute palliative care ward who were knowledgeable about the phenomenon under study. The researcher was familiar with the clinical area and therefore was able to seek out and select nurses who would be able to represent a perspective on delivering end of life care in an acute setting on a regular basis rather than a population of generalist nurses (Smith et al., 2009). One criticism of this approach to sampling is that there is no objective method for assessing how representative the group of selected participants are (Polit et al., 2001). The inclusion criteria was broad to include any nurse that was currently a palliative care nurse in an acute setting. All the participants were selected

from the palliative care unit within the acute hospital and therefore met the inclusion criteria of a palliative care nurse.

The researcher asked the Charge Nurse on the ward to indicate when potential participants are working a day shift on the ward and therefore available to discuss potential participation with the research. No presumption of willingness to participate was assumed by the researcher in identification of potential participants by the charge Nurse.

Potential participants were approached by the researcher during their shift on the palliative care ward, having been informed in advance by the charge nurse that an approach was possible and ensuring that ethical approval had been given. The researcher ensured that a suitable time was chosen to initiate discussion around involvement with the study which will did not impact on patient care. An open approach was taken when initial contact was made with the potential participant. A total of seven nurses expressed interest in taking part in the study and an information sheet (appendix 3) was distributed to allow the potential participant an opportunity to ask questions.

The contact details of the researcher, study supervisor and independent advisor were included within the information sheet The researcher then asked the potential participant to confirm their interest in participation of the study through email within fourteen days with the email address supplied on the information sheet. Following an agreed time limit of two weeks the participant was contacted again to arrange a face to face meeting to gain consent and organize a suitable time and date to carry out the interview.

6.6   Informed consent

Consent forms (appendix 4) were distributed to those expressing an interest in participating in the study. The researcher then arranged a suitable time and place to meet with the potential participant to sign the consent forms. The signed consent form was then filed and logged to ensure participation of the team members involved in the study could be audited. Care was taken to ensure only staff members who have given informed consent were included as participants in the study.

6.7   Data collection

Each interview was held in a quiet room close to the unit or another suitable location away from the clinical area which was convenient for the participant. The interview was also conducted at a time suitable for the participant and the resource needs of the ward which resulted in some interviews taking place when the participants were not on duty. This ensured the participant felt comfortable and allowed time for the interview to be completed without interruption or impacting on the ward resources. An interview schedule (appendix 5) was used to ensure data gathered was comparable across all participants. Smith et al. (2009) however advise that the schedule is only a guide and the questions may change in response to the material uncovered throughout the interview. It should be used as a virtual map to guide the researcher and a rapport should be established with the participant to ensure they are comfortable and able to speak freely. The data were collected through open-ended questions forming semi-structured interviews. There were initially three open ended questions to start the interview which would loosely reflect the research question and objectives and the interviews were completed within one hour. The nature of the open-ended questions allowed the participants to express their thoughts, feelings and concerns. According to Foddy (1996) open-ended questions should encourage the participant to say what they really feel without prompting or suggestion from the researcher.

6.8   Recording of interviews

Audio recording equipment was used to capture the interviews which ensured that data was recorded correctly. This allowed the data to be transcribed at a later date. Any nonverbal responses were noted to allow data to be analysed together with text segments according to the context in which they occurred as sometimes what is not said is as important as what is said according to O'Reilly (2009). Field notes were recorded following each conversation or interview. Smith et al. (2009) suggest making notes after the interview to reflect upon the impact the researcher's impressions of the interaction with the participant has taken. This allowed additional data to

be gathered which could be of some use later on in the process when analysing and contextualizing the data.

Field notes are a method of capturing salient points of an interview or observation that can be revisited and reworked in detail at a later date. The notes taken during the interview were brief which allowed the researcher to concentrate on the interview and were referred back to, allowing triangulation of analysis at a later date. There were also spoken field notes which were captured using the audio recording equipment. Finally the field notes were cross referenced to the interview schedule to allow the researcher to keep track of data and related observations to each interview, an approach recommended by Morse and Field (1996) A format for recording field notes was used. see example in appendix 6.

6.9 Role of the researcher in interviews

Reflexivity ensures the researcher thinks critically about the context of what is being researched and written. The process of carrying out analysis within IPA encourages a reflective approach and engagement with the participant and the data and therefore the analysis is a combination of input of the researcher and the participant. The researcher reflected on the interviews after they had taken place and carried out discussion with the supervisory team around the reflections and the analysis process. This process leads to a double hermeneutic approach as whilst the main aim of IPA is to understand the lived experience of the participant and the meaning they make of that experience, ultimately the results depend on how the researcher interprets those results or in other words how the researcher thinks the participant is thinking (Smith et al., 2009).

Smith et al. (2009) describe the interview process used in qualitative research as a "conversation with a purpose" which is informed by a research question. The researcher benefited through having knowledge of the nursing role within palliative care and an understanding of the roles and responsibilities within the team. This allowed a deeper engagement with the participants and ensured that the analysis was a combination of the

researcher and the participant, resulting in a double hermeneutic approach which is synonymous with IPA.

6.10 Risk to participants

In line with suggestions from Polit et al. (2001) participants in this study were given a debrief sheet (appendix 7) at the end of the interview thanking them for taking part and advising of dissemination of the results. Contact details of support agencies were included in the debrief information. This gave them the opportunity to discuss any issue or concerns relating to their "making meaning "of loss or death when delivering end of life care with an independent professional following their participation in the research.

6.11 Confidentiality and data handling

All identifiers were removed from the data to ensure anonymity and each participant was given a pseudonym. It was important to ensure confidentiality for the protection of the participant as all the participants came from the same ward, but also to ensure the author could freely narrate observations and reflections. Data were stored on a password protected lap top which only the researcher had access to. Hard copies of the data were stored in a locked filing cabinet in the researcher's office at Edinburgh Napier University.

6.12 Data analysis

According to Polit et al. (2001) qualitative data analysis can be challenging and labour intensive with few rules. Four styles of analysis are identified consisting of a quasi-statistical style which starts with themes that are pre-established and fit comfortably with descriptive statistical analysis. A template analysis style incorporates the use of a template to sort the data. Editing analysis in contrast involves interpreting the data using a categorization scheme and finally immersion or crystallization style which requires the researcher's immersion and reflection on the data.

Colaizzi (1978) developed a method of analysis for phenomenological studies which entailed seven steps as described in the methodology

chapter. Colaizzi's (1978) method is descriptive with the aim of finding common patterns or shared experiences from shared group experiences. The participants in this study had a shared experience of caring for th eddying in an acute setting. In contrast the process of carrying out analysis within Interpretative Phenomenological Analysis (IPA) encourages a reflective approach and engagement with the participant and the data. Interpretative phenomenological analysis (IPA) was developed by Smith et al (2009) and has its base in psychology however it is increasingly being used in other disciplines such a social, human and health sciences. It is qualitative research approach used to examine how participants make meaning and sense of their life experiences. Process diagrams for both Colaizzi and Smith's method of analysis can be found in the research methodology chapter (Figures 7, page 100 and Figure 8, page 103).

 The analysis is a combination of input of the researcher and the participant. This process leads to a double hermeneutic approach as whilst the main aim of IPA is to understand the lived experience of the participant and the meaning they make of that experience, ultimately the results depend on how the researcher interprets those results or in other words how the researcher thinks the participant is thinking (Smith et al,. 2009). The data from this study was analysed using an immersion style with a double hermeneutic approach. According to Smith et al. (2009) there is a connection and interdependence between the researcher, their data and their inherent knowledge which creates a dialogue around what the participant feels and how they make meaning of a particular phenomenon within the particular context which leads to a development of an account which is more interpretative in nature. The researcher conducting this study had first-hand experience of working as a palliative care nurse on a ward in an acute hospital and therefore personal experience did have some bearing on the interpretation of data and as such IPA was deemed to be the best fit.

6.13 Interpretive phenomenological Analysis

Smith et al. (2009) describe the IPA researcher as open-minded with patience, flexibility and empathy. They must also be willing to enter the world of the participant and respond to the participant within the context of their

world. It is based on the suggestion of Husserl (Husserl. 1965) that we should go "back to the things themselves" and differs from other analysis styles as its aim is to interpret the meaning of the content of the participant's account of a particular phenomenon rather than fix experiences of the participant into predefined categories' This approach is in contrast to other approaches such as those used by Colaizzi which whilst allow for analysis do not give the same depth as IPA as previously discussed in the research methods chapter.

6.14 Applying the IPA analysis process to the research data

The initial step of analysis involved reading and re-reading the written transcript to allow immersion in the data. Firstly **listening** to the recorded interview allowed for focus of the analysis. The second step was to **examine semantic content** and note anything of interest in one margin. The comments fell into three categories of **descriptive** where the focus is on describing what the participant has said, **linguistic** which explored specific language used and **conceptual** which involved the researcher engaging with the text on a more conceptual and interrogative level. The third step used the annotated text to expand the data and gain deeper insight into the meaning of the text. The annotations gave another level or perspective to the meaning of the text which helped to illuminate rich data. This was used as the focus for developing emergent themes. The volume of detail was then reduced but the complexity and interrelationships of the data maintained. This was achieved through working primarily with the annotated notes in the margin whilst breaking down the original whole interview into discreet parts to work on separately.

The interview became whole again once the analysis had been completed at the end of the process. Step four involved the mapping the themes already deduced but not all themes required as a distinct discussion around their content.   The scope of the research question guided the inclusion and blending of certain themes which allowed all themes to be included and therefore none were   discarded. A connection was then found between emergent themes. Step six involved moving on to the next transcript and repeating the processes already described. Care was taken to view the

transcript in its own right and ensure ideas gleaned from the first transcript were bracketed. Step six then pulled all the cases together to look for patterns across the transcripts and deeper levels of interpretation. A process diagram of the research design is illustrated on page 103 (Figure 8).

6.14.1 Looking for themes in Transcript 1.

Using this approach, each interview data was approached as a single piece of work. The first stage of IPA process involved listening to the recorded interviews to identify any pauses or inflection on the text which would not be identified through text alone. The interview was read and re-read over the course of a day with cross reference to the recording where necessary. The next stage of the IPA process required examination for semantic content and to facilitate this hand annotation was carried out the following day. Semantic content was examined and noted in the margin with descriptive, linguistic and conceptual comments being identified. The process of annotation and identifying sub themes from comments was an iterative process carried out over a couple of days to ensure the researcher could engage fully with the text at an interrogative level (Smith et al., 2009). The annotated text was then used to develop emerging sub themes. Using this process the volume of the data was reduced however the complexity and interrelationships of the data was maintained which informed the initial headings for the sub themes such as "being "or "death anxiety". The themes were then mapped against the text using the scope of the research question as a guide for inclusion of sub themes identified. Sub themes which did not appear to fit the aims and objectives of the research question were not discarded but identified and noted for discussion at a later stage. Emergent themes are then looked for, involving an analytical shift to review semantic content notes rather than the transcript itself (Smith et al., 2009). A further day was left between annotation and the use of Nvivo software (QRS. 2013). The process of inputting the data into Nvivo acted as a further stage in the analysis. The relevant text from each interview was highlighted and moved into a node which had been given a title such as "being or "death anxiety". A total of 14 nodes or sub themes were identified across all interviews. The nodes or sub

themes could then be refined further to create themes. The Nvivo software allowed the researcher to keep track of references in the text against the sub themes identified and ensured that data could be easily located for further analysis and comparison at a later stage. A validation process was followed, whereby participants were presented with the themes following analysis for further discussion and refinement.

In addition to the steps above the researcher enlisted the support of Dr Zoe Chouliara who had extensive knowledge and expertise around the IPA methodology. Dr Chouliara conducted an IPA analysis concurrently on transcript one. The findings from both Dr Chouliara and the researcher were cross referenced and explored to identify similarities and differences. Several similar themes were revealed through each analysis which confirmed the approach and quality of analysis of the researcher. The researcher then continued with the same approach throughout the analysis of the remaining transcripts using Nvivo to ensure references in the text were retrievable and set within a framework.

6.14.2   Looking for themes in subsequent transcripts

Following completion of initial analysis and recording of themes for one complete interview a further couple of days were allowed to elapse before starting the next interview. This was intended to allow the researcher to treat each interview as a single analysis and ensure the data was bracketed. The second transcript was approached in the same way as the first with initially listening to the recording, reading and re-reading of the transcripts to allow hand annotation which led to developing emerging sub themes. A connection between the themes of the previous transcript analysis was sought and explored further. This process was repeated with each subsequent transcript which allowed themes to emerge which in turn were collated into a framework which illustrated the connection between the themes previously identified.

6.15 Chapter Summary

This chapter described the IPA process of data analysis used for the study. A qualitative approach in general and interpretative phenomenological analysis methodology in particular was adopted, which underpinned the philosophical nature of this study.

Utilising this approach the researcher selected participants from the palliative care ward within the acute hospital. The names of staff working within the ward were provided by the senior charge nurse. Informed consent was given prior to collection of data. Data were collected through semi-structured interviews and digitally recorded and transcribed verbatim. Field notes were also taken throughout the interview to enhance analysis of the data. The analysis was then undertaken and the findings used to identify themes which were collated using Nvivo (QRS. 2013). Chapter seven presents the findings which emerged from the analysis.

Chapter 7
Findings

7.1   Introduction

This chapter extends the methodology described in the previous chapter and details the stages and action undertaken to recruit, collect data and analyse the results through stages of Interpretive Phenomenological Analysis (IPA). The resulting findings are presented after the description of the actions undertaken to develop the framework of themes and connections. In addition the researcher has included reflective accounts throughout the chapter to give some detail and background to the process of analysis. This approach helps to illuminate the findings and in so doing enrich the understanding of the phenomena.

7.2   Overview of IPA

The philosophical approach of epistemology best describes the relationships that exists between the interviewer and the interviewee (Creswell. 2007). The epistemological assumption in this research meant that the researcher became an insider and formed close relationships with the participants (Genzuk. 2003). The world view of the researcher also contributed to the approach taken. A social constructivism view lead the researcher to try and gain an understanding of the world they live in to develop subjective meanings. The participants own view of the phenomenon of grief they experience as palliative nurses working in acute settings was negotiated socially and developed through interaction with others. Analysing these interactions allowed the researcher to develop themes to illustrate the findings using inductive theory in the process of IPA.

7.3   Research Cohort

The research cohort was selected from a palliative care ward situated within an acute General Hospital in a semi rural southern Scotland. The unit has a total of eight beds and provides care for palliative and end of life patients

who cannot be cared for in other settings due to symptom management issues or psychological, social or spiritual needs. The function of this unit within a health board is unusual in the fact that it operates as a palliative and end of life care facility which has elements of care similar to a hospice but is situated within an acute hospital and therefore operationally aligns with the processes and procedures associated with an acute setting. The philosophical approach to care however is more aligned to that of a hospice setting.

The researcher previously worked alongside the research cohort as a staff nurse and end of life care facilitator and so had previous and an existing relationships with the group. The prior relationship of the interviewee and interviewer allowed the mutual trust and respect to shape and inform the development of the interview and added to the richness of the data gathered. The researcher was viewed as an authentic participant as they had an insider perspective as the researcher and also a background in palliative nursing in general but an authentic understanding of the issues facing palliative care nurses in acute settings in particular. The experience of the interviewer was one of mutual trust and respect with an innate knowledge of shared clinical experiences with the research cohort. Whilst there were several aspects which contributed to the researcher being able to glean information and data from the participants due to the close working relationship previously shared there were also challenges. Inferred meaning and assumptions on both part of the researcher and participant needed to be carefully managed and understood. The tensions identified added to the complexity and nuance of the data gathered. The real difficulties identified however were viewed as a positive contribution and helped inform the level of analysis and insight which is important in IPA. Field notes and reflection were used to mitigate challenges and are discussed further in the next section. Reflection 1. also outlines some of the researchers thoughts and emotions as the interviews progressed.

A total of seven nurses were interviewed, one male and six female with experience of the participants ranging from four to twenty years. All the nurses had experience in other fields of nursing but had worked on the palliative care unit for four years since it had opened. All the nurses were

part of the team on the acute palliative care unit but occasionally worked in the stroke unit if resources required them to move departments, in line with the operational requirements of an acute general hospital. The shifts undertaken in the stroke unit were infrequent and intermittent and therefore the nurses within this study would be identified as palliative care nurses in an acute setting. The interviews were carried out over a period of two months which allowed sufficient time in between interviews for the interviewer to remain objective in regards to each individual interview and treat each interview as a unique process before moving on to the next interview and the data contained within it. As field notes were recorded immediately prior to and post interview then the whole process could be completed in one step and stored securely until the next stage of analysis could begin. Analysis of the seven interviews was started once they had all been recorded and transcribed in line with the chosen methodology as described in figure 8 below.
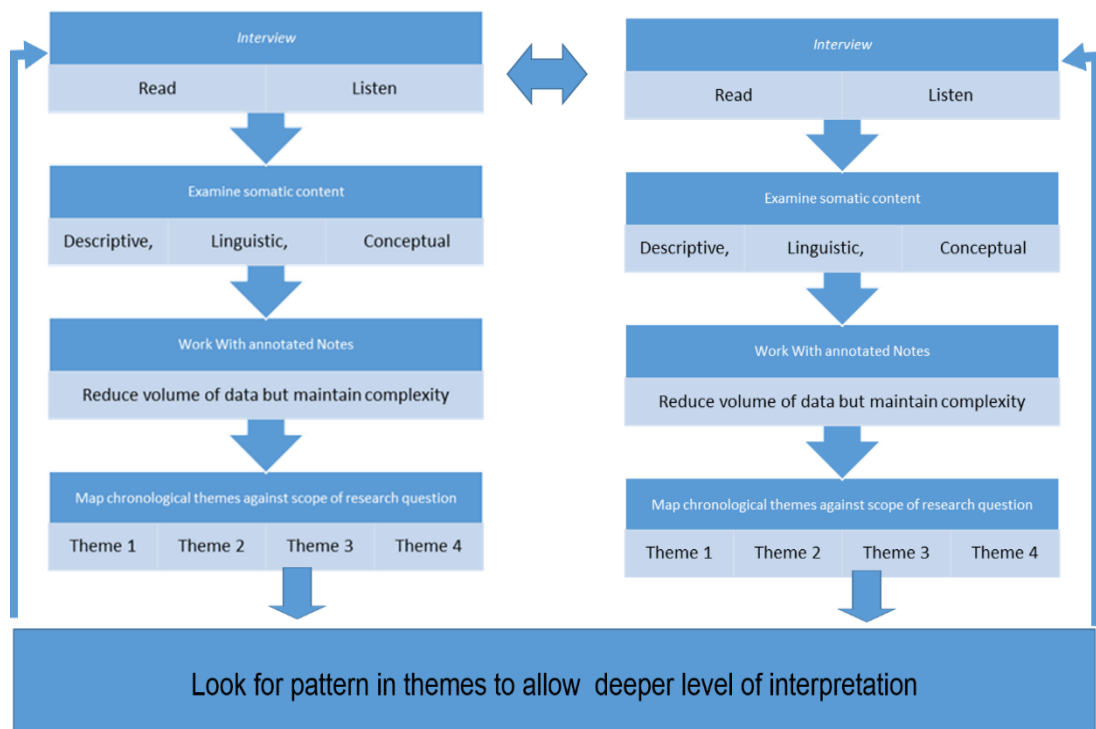
Figure 8 Proposed alternative method of phenomenological analysis according to Smith et al (2009)

Reflection 1. *Seeing myself as an authentic participant with an insider perspective.*

The idea and wish to carry out this research sprung from my time working as a staff nurse on the palliative care unit where the research cohort were recruited from. The challenges I and my fellow nurses experienced whilst working as a staff nurse were shared amongst my colleagues and often discussed amongst the team. I wanted to understand the impact of the work and the burden or insights understood by the team. I had a close working relationship with the current cohort of staff nurses as I had spent time working side by side with them delivering care to the dying and deceased. I changed roles and my current role of Quality Improvement Facilitator changed the dynamics but I still continued to work closely and build relationships with them. I was initially concerned that the participants may see the research as an extension of my role and a desire to improve the care given and therefore give answers to the questions posed that "fit" the expectations of a quality improvement project. I felt they may be guarded and see the interview as a test of their understanding and application of delivering care to the dying. From the very first interview however it became clear that the participants were initially apprehensive as the interview started and responded to the questions in a structured wayAs they relaxed and started to reflect on the care they had delivered and the feelings and thoughts experienced during the period of care they began to reflect and give much more insightful answers. They knew I had experienced some of the situations they were describing and felt I empathised with their personal thoughts and feelings. As a fellow palliative care nurse working in an acute setting I gained their trust and they perceived me to be authentic with an inherent knowledge. The terms they used and the situations they described did not need a further layer of explanation. The depth and breadth of their answers gave rise to some emotional distress for both themselves and I but acted as a cathartic experience for many of the nurses who thanked me for giving them time and space to revisit some of their experiences and emotions. They had not had an opportunity to reflect and consider their experiences and emotions previously.

7.4   Method of data collection

A semi structured interview approach was taken to allow the participants to express their thoughts and feelings about their lived experience of professional grief and delivering end of life care as palliative care nurses working in an acute setting. Three research questions were developed:

1.   What are the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying ?

2.   What is the palliative care nurse's response to the loss of a patient when working in acute settings?

3.   What is the meaning of loss and death experienced by palliative care nurses working in acute settings after the death of a patient ?

A review of the literature together with the research question lead to the development and design of a question prompt for use in the individual interviews with the participants. The question prompts were not intended to be used verbatim but rather as an aide memoire to ensure the interviewer stayed within a framework. The question prompts were related to the three research questions with the first asking the nurse what drew them to work in palliative and end of life care. The second question asked the nurse to describe their thoughts and feelings leading up to and after the death of a patient and the third sought to understand how the nurse managed their thoughts and feelings after the death of a patient. Each question also had prompts for discussion within the over arching discussion. An example of the full interview schedule can be found in appendix 5.

This ensured the interviewer covered all the relevant topics, adopting a systematic approach whilst allowing the interview to flow naturally and did not hinder the emergence of data relevant to each participant. The prompts were relied upon throughout the interviews with more emphasis being placed with them during the early interviews. As the confidence of the interviewer increased the prompts were referred to less frequently.

There are challenges to being an insider researcher not least to be able to demonstrate objectivity. Two further tools were used to mitigate the challenges including field notes and reflective accounts. The field notes and

reflective accounts also became data sets which were used in the final analysis.

Field notes were recorded immediately prior to and post each interview using the method suggested by Morse and Field which allowed the interviewer to capture thoughts, feelings and emotions immediately and in real time which gave a timely and accurate reflection of the researcher's experience of the interview process (Morse & Field. 1996). A field note recording template was used to capture observations and thoughts and can be found in Appendix 6. There were a total of seven field notes templates completed, one for each participant and reflection 2 describes the researchers experience of using field notes and reflection to prepare for forthcoming interviews. The field notes clearly tracked the confidence and perceived ability of the interviewer. Initial feelings of apprehension around the ability of the interviewer to carry out an interview of reasonable length and also cover all subject areas to enable enough rich data to be collected was evident from the first field notes recorded. Post interview field notes demonstrated that the interviewer felt satisfaction that their interview skills were acceptable and that the interviewee was willing and able to share accounts of feelings and perceptions around giving care at end of life. It became clear however as the interviews progressed that these interviews could potentially cause some distress not only to the interviewee but also the interviewer. The use of the field notes ensured the interviewer could refine the preparation of the participants at the start of the interview to add greater emphasis around the potential that they may become emotional or upset. The researcher was also careful to reiterate that the interview could be terminated at any point and resumed only if the interviewee wanted to as described in the document they had received as part of the informed consent process. The initial apprehension of the interviewer changed to anticipation prior to interviews being carried out as confidence grew and more data gathered.

The use of field notes contributed to researchers reflections after each interview had been completed. The reflections were audio recorded and contributed to the reflective accounts contained within the thesis. The audio reflections were played back and listened to prior to each new interview and

together with the field notes were used to prepare the researcher for the forthcoming interview. It was also important that the researcher was able to feel comfortable and competent to carry out the interviews but also to mitigate any negative impact from conducting the research for both the participant and the researcher.

Reflection 2. *Watching my confidence as a researcher grow.*

The process of recording field notes and reflections allowed me to map my thoughts and feelings against each interview and clearly tell a story of my growth in confidence and bravery to delve a little deeper into the answers presented. I initially worried about the structure and tone of the interview as I imagined the participants would give short answers and not elaborate on their thoughts and feelings. I had three main questions with prompts to help direct the flow of conversation but worried that the interview would not give enough rich data to contribute to the research. As the interviews progressed I became much more confident and realised that the participants were sharing some very powerful stories which I was sure would provide the depth and breadth required. The field notes and reflections also prepared me for the potential of the participants and myself to experience some distressing emotions which could be addressed at the start of each new interview.

Example of field notes

Interview 1.

I am worried that the participant won't be able to share their thoughts and may feel self conscious because they know me ?

What if the interview doesn't flow and only lasts a short time – will there be enough information ?

Safeguards were in place to ensure additional help and support were available to the participants of the study. A debrief sheet was given to each participant which listed contact details for sources of support from the Chaplaincy centre and the Occupational Health team should the participant

want to pursue further support outside the research study – see appendix 7. Polit Beck and Hungler (2001) suggest debriefing sessions are carried out after the data collection phase. The interviews lasted around 40 minutes for each participant and most interviews were paused at least once. The reasons for pausing the interview were interruption of the interview by other colleagues who required urgent information from the participant which could affect patient care. The participant asking to pause the interview to review and think about the question posed or reword an answer, some of the participants became emotional and the recording was stopped to allow them to take some time and feel composed before continuing with the interview. One interview was carried out in the participants home and the remaining six were carried out in an office close to the palliative care unit within the hospital. The location of the interview did not appear to impact on the breadth and depth of data gathered. The participants who conducted the interviews within a clinical setting appeared to be as comfortable with the process as the participant who conducted the interview in their own home. Each participant regardless of time or location of interview showed a willingness to express emotion, and showed openness and honesty in their answers. This was evident in the body language with open postures. Inflection of their voice and periods of comfortable silence added to the conversational and honest tone of the discussion. The researcher and participant were communicating within the framework of a connectedness or relationship with mutual respect. Comparison of the outcome and tone of the interviews also proved to be a sense check to ensure that interviews carried out were not viewed by the nurse as an assessment of their capabilities in a professional context.

The data gathered through the use of semi structured interviews was only one data set used for the research. Field notes and recorded reflections were also used to triangulate findings and add depth and breadth to the data. There were a total of seven interviews, seven field notes and seven reflections used in the analysis to develop and present the findings and discussion and ensure that reflexivity was managed appropriately.

7.5   Transcription process

All seven interviews were completed and the recordings then sent to a transcription service and returned for analysis, following the process developed by Smith et al. (2009) described in the following section. A transcription service was used for speed of return and to ensure accuracy of transcription. All identifying names or descriptions were removed and data was anonymised. The final transcriptions were read and sense checked before being returned to the individual nurses for their comments and agreement that the transcription fully reflected the interview they carried out. The nurses were given two weeks to read the transcript and reply with any comments, suggestions or amendments. All the nurses returned the transcripts with no changes required.

7.6   Inductive analysis

The analysis was carried out following the transcription process. Analysis was carried out for each transcript prior to moving on to the next. The initial steps of reading and re-reading the transcripts allowed the researcher to immerse themselves within the data and engage intellectually with the data and support inductive analysis.

The semantic content was examined which included descriptive, linguistic and conceptual engagement to fully draw out the analysis. This process involved annotation to the text of the transcripts which then allowed the researcher to reduce the refine the data but retain the complexity and interrelationships. The transcript and resulting analysis allowed the emerging themes to be worked upon as discreet components. An example of annotation of the text of interview 3 can be found in appendix 8.

The initial early themes that evolved in a chronological order were then mapped and then a refocus and consideration of the research question was used to ensure all relevant themes were included. Connections between themes were then identified. The process was repeated for each transcript in turn, ensuring insight gleaned from previous analysis of other transcripts was bracketed to ensure the researcher remained focused on the current

transcript. An example of one of the processes used to map the themes in interview 3 can be found in appendix 9

After each transcript had undergone the process, all the analysis was pulled together from each of the seven transcripts and patterns identified. This allowed a deeper level of interpretation and so inductive analysis revealed the four superordinate themes with layers of depth within the intermediate themes hidden within the superordinate heading. An example of this process for interview 3 can be found in appendix 10. Reflection 3 describes the researchers journey of illuminating the findings.

The transcripts were also loaded onto Nvivo (QRS. 2013) software to allow systematic logging and filing of analysis. Nvivo was used to further refine and collate relevant text from each interview and nodes created which could then be refined further to create intermediate themes. This added a further layer of analysis and ensured that all intermediate themes had been identified. The intermediate themes were then developed into four superordinate themes. An example of Nvivo analysis with the references and nodes used to develop the themes from all interviews can be found in appendix 11 The approaches described above combined to create the resulting intermediate and superordinate themes presented in this chapter.

Reflection 3. *Finding connection and meaning woven throughout all the data sets.*

I initially started the analysis on the first transcript with trepidation. I imagined that I would miss themes or miss code them. I initially undertook an analysis of interview one and compared this to analysis conducted on the same interview by one of my supervisors who was an expert in IPA. The analysis from both my supervisor and myself revealed similar themes and subsequent discussion confirmed a similar approach and thought process surrounding the themes. Following the initial analysis I became more confident but felt that I included many more quotes than required and found difficulty in grouping and refining the quotes and themes. I continued on with

the transcripts and revisited previous analysis refining my thought process with each new transcription. Patterns started to emerge and I was able to go back over previous analysis and identify quotes and meaning. As my engagement with the data deepened, I developed clearer insight into phrases, descriptions of the participants interactions with patients and the bereaved and the inferred meaning from their very personal stories of delivering end of life care in an acute setting.

I also listened to the recordings of the interviews whilst reading the transcript which helped to frame the quotes with pauses or inflection which added another depth to the inference of the quote. The field notes and reflection carried out after the interviews contributed to my perception of the data. I became aware of the concept of saturation where the same themes occur time and time again as I worked through the transcripts one at a time. This gave me confidence that I had thoroughly analysed the transcripts. To add another layer of trust and sit the analysis within a framework I used Nvivo which gave a level of confidence that not only had the analysis been carried out in a creative and intuitive way but it could also be analysed systematically to ensure I had captured all pertinent quotes. A further level of rigour became apparent as the triangulation between the quotes identified in the transcripts, the detailed field notes and reflections and my own experience of working as a staff nurse on a palliative ward in an acute setting consolidated the data and therefore the findings. One informed the other and added support to the interpretation of the quotes. I felt a very deep level of understanding, and therefore analysis was possible due to my unique position as a researcher, a colleague and a palliative care nurse.

7.7   Findings by theme

Emergent themes for each transcript were reviewed against the research question to ensure that they should be included and could be merged into meaningful descriptions. They were then collated to produce intermediate themes. The intermediate themes in turn were refined to produce superordinate themes. There were four superordinate themes identified ,1. The importance of being, 2. The altruistic self, 3. Separating the personal and the professional self and finally 4. Death anxiety and transference. Each superordinate theme is discussed in more detail in the following sections, the quotes used from each interview are presented and grouped together to lead the reader through the process of building the themes. The contribution of each transcript and quotes contained therein were layered and analysed from bottom up to build the four superordinate themes upon which the findings and discussion are based. See Figure 9.
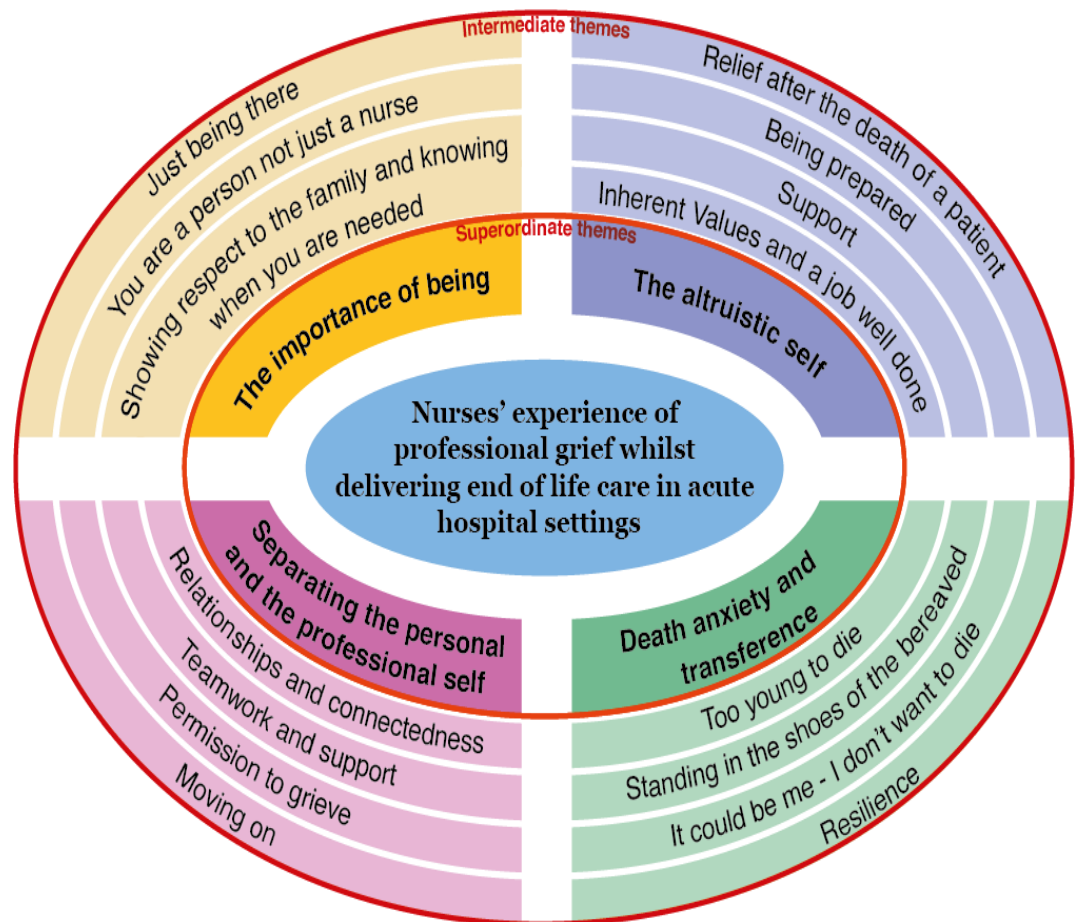
Figure 9 - Presentation of themes around nurses grief

7.7.1 Superordinate theme 1. - the importance of being

The title of this superordinate theme encompasses the belief that being with the patient and family members as the patient is approaching death or has died is a fundamental part of the philosophy of care for palliative care nurses in acute settings.

The theme was not explored directly through directed questioning but allowed to emerge throughout the interview. Six of the seven nurses interviewed mentioned being with the patient or loved ones specifically and referred to the importance of being at least twice throughout the interviews.

Three sub themes were identified which were: showing respect to the family and knowing when you are needed, the family seeing you as a person not just a nurse, and just being there. Table 3 illustrates the free coding and sub themes which led to the development of the superordinate theme of the importance of being. Each of the intermediate themes will be discussed with extracts from each interview to support the finding.

Free coding	Intermediate themes	Superordinate theme
Just being there – showing respect.	Showing respect to the family and knowing when you are needed	1. The importance of being
Just stood there with her in silence		
Not just a nurse	You are a person not just a nurse	
Important that they trust you		
Important they know you are there		
A lot of it is listening - Being there		
They see you as a real person		
Being there for people when they die.	Just being there	
Sitting knee to knee , just being there.		
we have to take a step back.		
Importance of being there		
Communication not always words		
Spending time with the patient		

Table 3 Table of themes for "The importance of being"

Intermediate theme - showing respect to the family and knowing when you are needed

The nurse discussed how they thought the act of being with the patient showed respect.

> *"it's to be with the patient and just try and... I don't know what you're trying to do when they're dying. You're just trying to be there for them I suppose. I suppose it's a form of just respect, isn't it? It's just respect for somebody else and respect for what they're experiencing." Nurse 7*

The nurse knew inherently that the presence of another human being who shared the care and concern for the patient offered support to those important to the patient. Through taking part in the bedside vigil albeit in a professional capacity and often for short periods the nurse was invited in to the sacred space of the dying and decease and those who mourn for them. This position also engenders a deep feeling of respect within the nurse as they acknowledge the intensely emotional and personal experiences of the dying and deceased and soon to be bereaved during the last days and hours of life. The respect afforded to the dying and those important to them is immensely important to the nurse who is present during this time.

Reflection 4. *Showing my respect*

This quote resonated with me as I understood from a position of experience what the nurse was trying to convey. Watching somebody actively die could feel like a hopeless situation but as a nurse you feel you are there to be a tangible comforting presence for the dying and bereaved. The sacred space you inhabit demands a respect which is afforded to those in your care and the unique situation that is unfolding before you. We are in a very real sense "*showing our respects*" to the dying and deceased

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Another nurse was asked about their thoughts and feelings when they were present at the moment of death for the patient.

> *"So now I've just learnt through experience just words aren't everything. Actions probably speak louder than words so just comforting somebody." Nurse 4*

They described a recent death where the wife of the deceased patient did not want to be alone, so the nurse stood quietly by – just being.

> *"I just stood with her just in silence. Just to let somebody know that you're there and it was just comforting, just a nice peaceful death, yes." Nurse 4*

The nurse offered the gift of presence to the wife of the patient. The intimation was that the wife of the dying patient did not ask the nurse to stay with them but again inherently, the nurse knew that their presence was needed and the bereaved did not want to face the death of their loved one alone.

The nurse conceded that the difficult part was knowing when to speak and when to stay silent and be a presence but felt that they knew when they were needed and could offer support without being asked.

> *"it's knowing the cue for that." Nurse 4*

Reflection 5. *Often what is not said is more important than what is said.*

Knowing when to stay with the family of the dying and deceased is sometimes difficult for the novice nurse, but through experience, I came to understand the body language, tone of voice or facial expressions as they witness their loved ones death. Nurse 4 understood the difficulties in reading the situation but bravery and confidence in your conviction is required to support the dying and deceased and offer the support they often silently seek.

Intermediate theme - you are a person not just a nurse

You are a person not just a nurse came through in four of the seven interviews. Nurse number one discussed grief for the patient being unlike grief for a family member.

> *"I think the relatives realise that you are actually human as well and you're not just this nurse machine person who's running about doing everything that I think they turn around and they see you – they really see you" nurse 1*

The nurse described how they need to remain professional and care for the dying and deceased but often they experience periods of sadness for the patient and their loved ones as death approaches. Often the loved ones appreciate the care and concern and understand that the nurse is also a fellow human being with thoughts and emotions. The loved ones acknowledge the emotional labour imparted throughout the care of the dying and understand that the nurse is a person – they really see them.

Reflection 6. *When your more than a nurse*

I can associate with this quote as a nurse caring for the dying. The family often form a relationship with you. They understand and appreciate your role as a health professional but often they acknowledge your presence as another human being. Family members in the past have enquired how I am feeling and ask how do I cope with death and dying and bereaved family members. When saying goodbye to family members after the death of their loved ones they often instinctively come to give a hug or a touch of the arm as if human contact is a sign of their gratitude and support for the nurse. As nurse 1 said they "*really*" see you. I acknowledge and appreciate their care and concern as I feel they need to show their appreciation of being supported through a difficult time.

Nurse number seven spoke about being there as a person and not a nurse.

> *"the family, they just want somebody there…. You become suddenly...you're not as much of a nurse. You're just somebody that's there, you know. So, it's just, like, somebody there..." nurse 7*

Nurse five was asked directly about the moment of death and the nurse being present. They felt wanted and appreciated as a person, not "*just*" a nurse

> *"So sometimes when the death is quite peaceful and comfortable and the family's upset and they want the nurse to be present at this time it's actually quite comforting knowing that they actually trust me, and they want me to be with them because they feel comforted by my presence there." Nurse 5*

In contrast to the feelings of comfort and acceptance, the nurse described a situation where the patient was experiencing a difficult death. The nurse experienced anxiety of the thought of the patient dying alone. The act of being with extended to patients who had no body to be with them as they died and the nurse felt this was a fundamental act of care to ensure the patient did not experience death alone and had another person to offer comfort and support often throughout a very frightening time.

> *"If the patient was very anxious and was dying in a difficult circumstance that's completely different situation for me. I feel anxious too because obviously…and upset. I had situation which some of my patients who were dying with me they never had families which is quite upsetting because you don't want anybody to go on their own and quite often the situation is a very busy ward, so we couldn't sit with the patient. I couldn't sit with the patient." Nurse 5*

> *"I felt very actually useless. I felt that I couldn't keep the patient comfortable because it's quite a traumatic situation." Nurse 5*

Nurse three also spoke about the importance of talking with and listening to the patient and their families. The inference from this conversation was that communicating with the dying and bereaved has great importance and the power of presence through discussion and shared experiences has a big

impact. The nurse admitted that initially the act of communicating under such difficult and emotional circumstances was difficult but through experience they learnt to identify the need and benefit and were able to utilise the skill to support the patient and those important to them. To share the journey as a fellow human being.

> *"I think something that I've found hard to do…to start with, when I first started training is you've got to listen what…a lot of it's just listening, just being there. You know, just talking and talking and talking to them" nurse 3*

Intermediate theme - just being there

The intermediate theme of "just being there" emerged in five of the seven interviews carried out. Nurse three was asked why they preferred palliative and end of life care nursing to other areas of nursing. The nurse described the additional factors of empathizing and making a difference to patients. The nurse described the deeper emotional connection they have when caring for patients at end of life which differed to generalist nursing. They could not fully articulate the deeper connection but knew their thoughts and emotions differed to those they experienced when caring for a patient where there was curative intent.

> *"...you get time to empathise with others and just to make a difference to them. I mean, I know in other nursing you can make a difference to continued life and all the rest of it, rehab and that sort of thing, but I just…there's just something about palliative care" nurse 3*

Nurse five compared working in other areas to the palliative care ward as very being very different and echoed the thoughts of nurse number 3.

> *"In general medical wards nurses are actually very much focused on their tasks, medical tasks, how to improve their quality, know how to make them comfortable, people comfortable and provide the palliative care but they actually are very active with treatments.*

Quite often in palliative care we have to just take a step backwards and just provide the palliation instead of providing active treatment. So, I think the way we act and how we deliver the care that's the difference." Nurse 5

Reflection 7 – God will look after him won't he ?"

The need for the presence of another person is often most keenly felt in the small dark hours of the morning. This observation was made whilst I was a nurse working on the palliative care unit. It was common for patients to be wakeful and anxious overnight. Management of physical symptoms such as nausea and pain could usually be successfully delivered to support and reassure the patient. Occasionally however the patient was unable to describe their needs and wants but were extremely anxious and often frightened. I recall one patient who was similar age to myself with a child of a similar age to mine. The patient knew she was dying and had been busy that day arranging her affairs and the future care of her child. Throughout the night I noticed that the patient was awake each time I checked but denied any pain or other symptoms. I decided to offer the patient a cup of tea and sit with them a little while. The patient slowly started to talk about her fears for the future for her son. We discussed the plans she had made and the support her son would have. She began to reflect on the care and love her son would receive from her extended family and began to feel a little better. She thanked me for being with her and talking about her son and ended the conversation with "I know he'll be Ok – God will look after him won't he ?". I replied I thought he would and left the room. I became emotional after I had left the patient as I associated with her age and the similar age of her child to mine. I imagined being in the same position seeking reassurance that God would look after my child. I felt also that if I was in the same position I would want to talk to somebody about my hopes and fears who was not connected to the situation, who would listen and empathise and let me speak but mostly just be with me.

When asked about their thoughts and feelings when they were present at the moment of death for the patient. Nurse number four said that words are not everything – presence sometimes has a much more forceful impact.

> *"So now I've just learnt through experience just words aren't everything. Actions probably speak louder than words so just comforting somebody." Nurse 4*

Nurse seven talked about just being with a mother after her daughter had died. The nurse was actually reflecting on their own role as a mother and could empathies with the bereaved. The nurse wanted to offer support to the bereaved mother and by sitting knee to knee there was an unspoken act of support, knowing and compassion.

> *"And a previous time I sat with a mum when her daughter died, and her daughter was only in her early thirties. And her daughter had actually a baby and a toddler and her husband had gone away with the kids and it was just the mum, and I just sat actually knee to knee with the mum at the bedside ... probably times when you can empathise with them a wee bit" nurse 7*

Reflection 8. *A mothers knee*

Of all the quotes in this section the picture painted by this abstract resonates with me the most. The nurse describes sitting knee to knee with the bereaved Mother which brought to mind a strong image of the nurse sitting close to if not touching knees with the bereaved Mother in silent support. The other association is that of a Mothers knee – a safe, secure and loving place where the Mother can enfold and protect her child. The unbearable grief experienced by the mother watching her daughter die was felt by the nurse delivering care. The Mother could not enfold and protect her adult child. We are not just one dimensional but made up of many facets and the role of a mother is fundamental in our being. The image is of someone knowing and being there and fully present. Support from one mother to another, physically knee to knee and spiritually through silent support.

Finally nurse six discussed a patient and family she had developed a relationship with. It was important that the nurse could provide care which would contribute to a good a death as possible. It was important that they were able to support the dying and bereaved and that they personally could affect the quality of death for the patient.

> *"It's just, it's knowing that you can be there for people at a time that's really important, and make sure that you can see that it can be kind of as good a death as it can…just being there for the family and the patient. " nurse 6*

7.7.2 Superordinate theme 2. - The altruistic self

The title of this superordinate theme covers the phenomena of altruism within palliative care nursing in acute settings. There were four intermediate themes; Inherent values and a job well done, Support, being prepared and relief after a patient had died. See Table 4.

Free coding	Intermediate themes	Superordinate theme
Felt they inherently could cope.	Inherent Values and a job well done	2.The altruistic self
Feeling responsible for a "bad" death.		
Making a difference.		
Palliative care more for them.		
Basic nursing care – holistic care.		
Inspired to work in PC		
People die in all areas		
Need to do a good job.		
Felt they could do the job and do it right.		
A good death then they feel OK.		
Own personality comes out – inherent way of caring – instinctive.		
a job well done.		
Support for patient and families.	Support	
Taking their worries away.		
Need to be prepared and in control	Being prepared	
Leading up to death feel anxious – want everything to go smoothly.		
Focus on being prepared for the death.		
Can be a blessing and feelings of relief when patient dies.	Relief after the death of a patient	
Relief when someone dies.		

Table 4 Table of themes for "The altruistic self"

Intermediate theme - Inherent Values and a job well done

Inherent values and feeling responsible for a job well done emerged across all the interviews carried out. Nurse one discussed how they felt they could manage repeated incidents of death or instances of patients and families requiring support. They acknowledged that witnessing and supporting throughout multiple deaths did have an impact but they felt they were able to

manage their emotions. They saw the delivery of care to the dying as part of their job and something that was expected of them. They took comfort in being able to offer support to the patients and relatives and qualified their ability to cope with the fact that they did not become depressed through caring for the dying. They inherently knew that they were needed and strived to deliver the best care they could.

> *"A lot of people say they couldn't do it every single day but I felt that I maybe could, but you really don't know until you try." Nurse 1*

> *"Quite a lot of sad cases, stories, situations and I always sort of managed…I was okay with these kinds of things. I never ended up on antidepressants and depressed and all this. I just…obviously I did it, saw it as my job and I was there to support patients and relatives. "*
> *nurse1*

Nurse five described how busy medical wards were delivering care to palliative patients, but favored an active approach to treatments and interventions and did not have the philosophical approach or values of a true palliative approach to holistic care. They discussed taking a step back to see the holistic view and provide supportive care to the dying. They described that they were different to nurses delivering generalist care and felt this was the right approach which they understood to benefit the patient and their loved ones.

> *"In general medical wards nurses are actually very much focused on their tasks, medical tasks, how to improve their quality, know how to make them comfortable, people comfortable and provide the palliative care but they actually are very active with treatments. Quite often in palliative care we have to just take a step backwards and just provide the palliation instead of providing active treatment. So, I think the way how we act and how we deliver the care that's the difference."*
>
> *Nurse 5*

"Then it just made me think this was more the kind of nursing where you could be, like, more hands on and deal with a patient, like, look after the patient and their family and do more for them." Nurse 5

Nurse five went on to describe how they provided hands on care and looked after not only the patient but their family also. Understanding the needs of a dying patient was described as doing more for them. These needs are the less of the need for direct interventions and curative intent but much more in regards to what the patient and the family really needed at that time. To care for them in the human aspect of care and support them through a very difficult time to the best of their ability.

Reflection 9. *Trying to deliver good quality palliative care on a busy ward.*

Nurse five describes caring for the patient and family in a person centered holistic way. We are taught as nurses to take this gold standard approach and I empathised with the desire to deliver care in this way. I often found it difficult however to be able to deliver care which really fit this criteria. As nurses working on a busy acute ward, albeit with a palliative care approach time and resources were often an issue. My colleagues and I often discussed the feeling of needing more time to support the patient or family emotionally but coming under pressure to complete the tasks required on a busy ward. I think the nurse was describing the philosophy of care and how she would like to deliver care.

Nurse seven talked about their personality and how this influenced style and approach to nursing. They discussed the concept of no right or wrong approach to palliative and end of life care but the instinctive desire to deliver care in such a way that is intuitive to them and meets the unspoken need of the patient or their family. They felt the care they delivered was a better quality of care due to their intuition and felt they achieved a positive outcome and a job well done.

" But your own personality comes out a lot. There's not often a right and wrong answer to palliative care to be honest and it becomes I think very instinctive over the years." Nurse 7

"kind of, like a family. I think you get a different atmosphere in these kind of areas and it, kind of, gets under your skin. I find it quite compelling. I find it horrendously frustrating as you probably know. But it's quite compelling and you, kind of, try and get away from it but it, kind of, draws you back. Well, it has me anyway." Nurse 7

Refection 10. Being drawn to palliative care

Nurse seven spoke directly to me as a fellow palliative care nurse "*I find it horrendously frustrating as you probably know*". The shared experience of delivering care to the dying and deceased and the accompanying challenges were implied from one professional to another. The inherent knowledge and altruistic tenants are all clearly evident in this full quote – we are drawn back to palliative care, almost as if we have a sub conscious need to care for the dying. It reminded me of a GP when speaking at a palliative care conference describing working in palliative care as being pulled into a whirlpool that soon spat you out if it wasn't right for you - or indeed you for it.

"*How can you work in that area with all that sadness?*" is a frequent response when discussing your role with friends and family but also, I thought, surprisingly from other nurses. On reflection palliative care is "*not for everyone*" and I think often overlooked when nurses in generalist are required to deliver end of life care.

Nurse seven went on to describe how delivering palliative care was compelling and this was built on the desire to provide care which the patient and family needed and fulfilled a need within the nurse to deliver the best care possible to the dying.

Nurse three also described palliative care as something special. They were asked why they preferred palliative care nursing and they described how they enjoyed the feeling of making a difference to their patients which the

philosophy of care in palliative care supports wholeheartedly. The inherent need to provide good care for the dying patient and their family is described as being ingrained in the nurse delivering palliative care.

> *"I mean, I know in other nursing you can make a difference to continued life and all the rest of it, rehab and that sort of thing, but I just…there's just something about palliative care" Nurse 3*

Nurse seven describes a feeling of satisfaction when they had made a difference to a patient and their family and given them the best care they could. The nurse described their frustration around constraints of resources and how this could affect the perception of the nurse. They may feel like they were prevented from delivering good quality care but when the quality of care was achieved this mitigated the feeling of frustration. A feeling of satisfaction was achieved from care delivered well.

> *"And you get a great deal of satisfaction, because you really feel like you make a difference and I think in nursing nowadays a lot of people don't feel like they make a difference because of the constraints in the NHS shall we say. So you do get a lot of job satisfaction I suppose, yeah." Nurse 7*

Reflection 11 – delivering palliative and end of life care within a resource scare model

Recent personal experience working as a staff nurse on a Covid ward within the hospital highlighted the reality of caring for the dying in an acute setting. My expertise as a palliative care professional and approach to caring for the dying did not fit into the fast paced, resource scare model of care being delivered. Compassionate and empathetic care was being delivered by the team on the ward, but to a personal cost to the nurses which comprised of additional effort, reduced capacity to carry out non urgent tasks and little or no time for reflection.

In relation to the death of the patient, nearly all the nurses equated a peaceful death with a job well done. The emotional labour required is lessened when the patient is comfortable with symptoms under control. The nurse can provide care and instigate the attendance of the family which may

contribute to the patient approaching a gentle death in the presence of the family. The nurse feels they achieved their own professional goals.

> *"Sometimes I think because we do it that often and sometimes it doesn't affect me emotionally. I think that's more so if it's expected, if the patient is really settled and peaceful and they slip away and if their family are there ." Nurse 6*

Conversely if a patient experienced a difficult death through pain or anxiety then the nurse felt responsible and did not feel they had done a good job. The nurse conceded that the team did try to manage the patients symptoms of pain and distress but this proved difficult even with optimum doses. The nurse understood that they had followed protocol and delivered care to the best of the teams ability but felt they had failed the patient in not achieving a good death for them. The nurse describes how they felt very emotional and cried with the patient and their son and felt regret. They felt they had let the patient and their family down, they felt responsible for the emotional and physical pain for all involved in the death, even though they knew this was irrational. The experience of delivering care to this family and witnessing a distressing death had long lasting effects on the nurse. There is a cost to the work of delivering palliative and end of life care. The altruistic nature of the nurse propelled her to deliver care to the best of her ability and care for the patient and her son but the emotional labour involved in this act of caring weighed heavy on her thoughts and emotions long after the patient had died. Reflection 12 describes my emotions as I witnessed the distress of the nurse and reflected back on my own experience of caring for the dying and deceased.

> *"Just I think not getting on top of this lady's, it was just her symptoms she was having was so distressing to see and we just couldn't get on top of it with the amount of medication that should have knocked out anyone, she just got into that point where nothing was hitting her." Nurse 6*

> *"it was awful, like, I couldn't stop, I was crying with the patient, with the patient's son. I just felt I wasn't doing my job right and I wasn't doing, like, I just wanted this lady to be comfortable and*

everything that we were doing wasn't helping and that felt awful. "
Nurse 6

"This night, it was - I just couldn't believe that everything we were giving this lady just wasn't helping her at all. It was just quite distressing to see somebody dying like that. …Yes it was just one of the most traumatic things I've had to deal with" Nurse 6

Reflection 12. *The emotional labour of caring for the dying and deceased.*

This point in the interview the participant became distressed. I also became emotional as I had cared for the patient and her son prior to this occasion. My sadness was not only for the patient experiencing a distressing death and her son witnessing it but also for my colleague who felt so helpless and was clearly distressed at the memory of the event. The interview was halted and I asked the participant if they would like to stop. They replied that they would like to carry on and they had not spoken about the event in such depth before but found it helpful to explore their feelings surrounding it. I felt at that point that the research I was carrying out had an indirect consequence of giving something back to the participants – the opportunity to speak openly about issues that they had previously hidden or played down. It's Ok to be sad and its good to acknowledge the connection they had.

Nurse two described their feelings of being responsible if a patient did not have a good death. They described how witnessing a distressing death left them feeling vulnerable and responsible. Only through experience could the nurse come to accept that they delivered care to the best of their ability but sometimes optimum symptom management could not be achieved. They eventually did manage to come to terms with the fact that they had delivered care to the best of their ability and that in itself was a job well done.

"Sometimes it's not always possible. So there is that worry and anxiousness that it may not be the best it can be for that person. Accepting that it sometimes isn't was the hardest part for me. That

took me years and I often went home really upset when I didn't achieve it. Coming to terms with the fact that you can't always achieve it was probably the biggest thing." Nurse 2

Intermediate theme – Support

The importance of support for patients, family members and each other was a strong theme throughout all the interviews.

Nurse four describes making the patient and family members feel safe. They wanted to support the patients and their family and care for them and take their worry on as their own, to allow the family and patient to concentrate on being with each other in a calm environment. The nurse felt that by being professional and in charge of the situation they would make the patient and family feel they were in the best hands. The nurse hoped that worrying about pain or symptom relief or other components of care would be handed over to the nurse allowing a peaceful time for the patient and family as death approached. This was seen as a right of the patient and family and something that they deserved which was within the gift of the nurse to offer.

> *"Support and, you know, you want them to feel safe as well. You want them not to worry so you're taking worry away from that person…. I think it's quite comforting to know that you're going to be looked after." Nurse 4*

> *"… I feel that I'm just doing, well, not a service but I feel like I'm doing something that they deserve" Nurse 4*

Discussion with nurse five took place around how it was equally important to support the patient and the family members. The context of this quote is within the patient and family wishes sometimes being different to each other. The duty of care is to meet the patient wishes but family considerations also have to be taken into account particularly if the patient is unresponsive. Differences may be between the desire to be more sedated or not, requesting visiting to be stopped or other issues. Family members may find it difficult to understand patient's wishes and the nurse must be skilled at navigating the care for the patient and the care and support for the family member.

"I feel quite often anxious, generally anxious simply because if I know the person, I know their wishes, it's difficult sometimes to make their wishes. Quite often people dying, they want to be comfortable. They want to be peaceful. Sometimes actually to give them the peace and keep them comfortable is quite difficult." Nurse 5

Nurse seven agreed that it the patient and family need support and they try to make them feel at ease. Skill lies in understanding the needs of the patient and of the family and being able to address these individual needs within the context of care. The nurse provided support to ensure the patient and family felt at ease and had confidence in the nurses ability to provide good care.

"just trying to make the family feel at ease, trying to make the patient..."

"...I just focus on what's needed, what the patient needs and what the family need and how I can try and provide that." Nurse 7

Intermediate theme - Being Prepared

The importance of preparedness arose in six of the interviews. Nurse five said that they felt anxious leading up to a death. To mitigate feelings of anxiety the nurse routinely ensured that everything was in place should a crisis arise regarding symptom management or anything else. Anticipatory medication prescriptions were checked and any goals of care discussed with the team handing over. The nurse would ensure that they introduced themselves to the patients and family present on the ward.

"I would feel anxious if I can't keep the person comfortable and peaceful for the last few hours of their life". Nurse 5

Nurse two also uses the term anxious to describe their feelings leading up to the death of the patient. Through ensuring everything was in place the nurse created a feeling of security for themselves and the team, safe in the knowledge that they could deal with any situation. They felt it was their duty and responsibility to ensure the patient had a good a death as possible. If they were able to provide the best care they could and had everything prepared with an understanding of the care needs of the patient and the

dynamics of the family relationships, they felt armed with the power to help their patient.

> *"It's a really anxious time, you're anxious for…well you know how things are working on the unit at the moment, we have to check the Kardexes and check that all the anticipatory meds are there and sometimes that's not happening. So you're anxious about…I always check these things when I come on shift and get them sorted as quickly as I can, you know. It's more difficult at the weekend. But you're anxious that…you know, that that patient is now coming to the end of their life, are they going to have a good death or a bad death, that is part of your role to ensure that it's as best as it can be for the patient and the relative. " Nurse 2*

Reflection 13. *The lack of feeling prepared for Covid.*

This became very apparent whilst working on the Covid wards during the pandemic. There was often a great sense of lack of preparedness from the challenges ahead. My knowledge and skill in delivering end of life care became a much needed source of support for other nurses on the ward. The nurses had been pulled from other areas and some had little experience of caring for dying patients. The complexities and uncertainty around Covid added to the anxieties of the team around delivering end of life care. The lack of feeling prepared added to a sense of reduced confidence and competence and resulted in feelings of inadequacy for some of the team. As time wore on more and more was being learnt about Covid and symptom management and expected trajectories etc so confidence levels increased within the team but the crucial element of being prepared, particularly in the case of a deteriorating patient became paramount to the care delivered.

Nurse seven compares the process of being prepared to that of solving a puzzle. The care of each patient is unique to that patient. Symptom management, physical, social, spiritual and psychological care can differ significantly from one patient to the next. Family dynamics add another layer of complexity which the nurse needs to navigate and understand to deliver

good quality end of life care which meets the patients needs. In the following quote the nurse describes how the differing component parts feel like a puzzle which they have to solve. They give themselves to the care of the patient for the next few hours and make that the focus of their attention.

> *"it's almost like solving a puzzle, it's trying to work out how best to get from where you are to where you want to be with things like medication, communication, just trying to make the family feel at ease, trying to make the patient...so that's all that's in my head is just what my job is for the next few hours." Nurse 7*

Nurse four also approaches the death with a strategy of preparedness. Being prepared makes the nurse feel more confident and competent. They mention control, they want to control the pain and suffering and give support to the patient and the family. They do everything in their power to be prepared and provide good care which would in turn prepare the patient and the family for the forthcoming death.

> *" Prepared, yes, I feel confident and secure when I'm doing things like that and I feel confident in the fact that I can make a decision … I'm a very systematic person so I like to feel that everything's in control." Nurse 4*

> *"Just doing that, you are kind of doing everything you can at that point for them - you feel like you are doing your job." Nurse 6*

Intermediate theme - Relief after the death of a patient

The final intermediate theme from this superordinate theme was that of relief when a patient dies. Four of the nurses explicitly speak about their feelings of relief.

Nurse one was asked to describe how they felt at the moment of death of the patient. They described how it was a blessing for the patient, as if the death was a final and good conclusion which would stop the pain and suffering. Although it could seem counter intuitive death was welcomed as an end to pain both physical and emotional.

"It can obviously be emotional but it can almost...I think sometimes you can feel it's a blessing for the patient as well if they've had a really difficult time and you know what they've all gone through. I think you feel relief for them as well. "   Nurse `1

Nurse seven also commented on the relief felt after a difficult death. The nurse described how the pain had stopped for everyone. This includes the patient, family members but also crucially the nurse. They had tried their best to help the patient achieve a good death and the cessation of life had stopped the pain for all involved, including themselves.

" Sometimes to be honest it's a relief if you've had somebody that's had a really difficult death and they die it's, like, you know, it's, kind of, stopped for everybody, that, kind of, pain." Nurse 7

Nurse two described the period immediately following a death as a time which held a lot of relief. Death was seen as a positive outcome. They understood that it could not be prevented, but by ensuring the dying and soon to be bereaved were well cared for they felt they had played their part in giving comfort.

" probably a lot of relief for the patient and the families and if it's been a good death then, you know, I look on that as a good thing for everybody. So I'll look at it as more a positive thing" Nurse 2

Nurse three explains how the nurse's grief for the patient following the death can be mixed with relief. Again the nurse can feel sadness for the loss of their patient and empathise with the grief of the family but through providing comfort and care they hope to mitigate the feelings of despair. Their altruistic approach not only goes some way to ameliorate the bereaved family's feelings of loss but also serves to give the nurse comfort that they did help the patient and family members through a difficult time.

" but when there's family and that there, the biggest feelings will be for their grief, their loss. And then it can be mixed with the feelings of relief that they're sometimes feeling that the patient's no longer suffering." Nurse 3

7.7.3 Superordinate theme 3. - Separating the personal and the professional self

This superordinate theme explores separating the personal and professional beliefs and values held by the nurse. The themes were apparent in all seven of the interviews conducted. There were four intermediate themes identified which were, relationships and connectedness, teamwork and support, permission to grieve and moving on. See Table 5.

Free coding	Intermediate themes	Superordinate theme
Relationships are formed and do impact on you .	Relationships and connectedness	3.Separating the personal and professional self
Conflict of being "professional" and developing relationships with patients and families.		
Difficult when looking after somebody you know.		
Relationships affect how you feel about a death.		
Last respectful thing I can do.		
Good close team is really important	Teamwork and support	
Support colleagues through group reflection.		
Best nurses don't get emotional – trained by old school		
Not professional to show grief but admit that they do get upset	Permission to grieve	
It wasn't nurse's grief to deal with and wouldn't disrespect family by assuming that it is.		
Good PC nurses don't show emotion.		
Question themselves – too unfeeling?		
Importance of reflection.		
Describe it as sadness not grief – call a halt to grief.	Moving on	
Short burst of grief – move on to next patient.		
Need to move on to look after the next patient the next day		
Clear your head – new slate then move on.		

Table 5 Table of themes for "Separating the personal and the professional"

Intermediate theme - Relationships and connectedness

This intermediate theme was discussed by five of the nurses.

Nurse one talked about having a big relationship with their patients. The inference of big could translate to a deep relationship. The relationship was important to the nurse and they wanted to care for the patient to the best of their ability. Relationships were important and were mutually beneficial for the dying and the nurse alike.

> *"I know sometimes it was difficult for me as well because I did have a big relationship with some of these patients, well - . So I did have big relationships with some of them but you obviously…you just knew you were doing your best for them, basically." Nurse 1*

Nurses three and five explained how they became more involved. They described becoming personally involved, especially over time as the relationship with the patient and family deepened. They understood that they "should" show a professional side but sometimes emotions did run deep and relationships did develop. They tried to be professional but acknowledged it was difficult not become attached. The nurse is also a person with their own set of empathies and emotions and tried to weigh their own feelings of loss and grief against their assertion that they should not show their feelings and remain professional.

> *"You're still giving the same care, no matter how long you've known them, but obviously you've got a bit more personally involved if you've known somebody a bit longer or if you've got an attachment to somebody… you do get closer to some patients than others" nurse 3*

> *"Obviously most of us, like myself, I'm getting attached to the patient and especially when I know them more and I know their families so you won't or you don't, you're getting attached to them so obviously it's an upsetting factor in this way too. - if we build up the relation with the families, when you see people upset obviously they're losing their loved one, it's upsetting. Then obviously we're professional policy here. We don't want to show the feelings. We just*

want to be there to help people who can, they can come and cry to but obviously if we got attached, we are getting emotional too. I don't try to show my emotions." Nurse 5

When nurse six was asked about their thoughts and feelings leading up to a death they said that depended on how well you knew the patient. The nurse describes a personal relationship that may have developed over the period of care. They did assert however that a personal relationship may not develop with every patient and their depth of connectedness has a direct impact on their depth of feeling around grief and loss.

"think it always depends on whether you know that patient - I think it does affect you differently if you know them, like if you've gotten to know them more personally. " nurse 6

Nurse two described the final act of care for a patient. A nurse may have spent a period of time caring for the patient and their family and feel that providing the final act of care is a parting gift of care they can give to the patient. To wash and prepare somebody to receive their family one last time before they are removed to the mortuary is an important ritual that the nurse feels allows them to say goodbye to the patient and ensure the family have a good experience as possible when they say their last goodbyes to the patient. The nurse described feeling at peace, all be it with a feeling of sadness, following delivering the final act of care as they felt they had met the needs of the patient, family and themselves.

" last offices is the last respectful thing I can do, so I'm at peace. You know, I don't feel…I'm sad again but it's the last thing I can do for that patient. So no, I think that's when I'm…if it's all went really well, then I'm fine, yeah." Nurse 2

Reflection 14 describes the researchers first episode of delivering care after death. It is an opportunity to bring the episode of care to a close and chance for the nurse to reflect on the person and the care delivered.

Reflection 14. *They are still our patient*

The first time I was called upon to provide last offices or the final act of care I was a student nurse. I was apprehensive but given advice by the nurse mentoring me to address the patient by their name – they are still our patient. This advice put the process into context. The patient had been a member of the armed forces and liked to be referred to as Major. He was a very proud man who liked to be shaved and well presented every day. I addressed him by Major and washed and dressed him and felt he would have been grateful for the care taken in his appearance. He was afforded the same respect in death as he had received in life and this allowed me to reflect on the care he had received and feel honored and proud to have been a part of that care.

Intermediate theme - Teamwork and support

This intermediate theme appeared in four of the interviews.

Nurse two described how the team worked together when delivering palliative care. The team were described as close and dedicated. Support extended to each other with the inference that this support and closeness was not always found in other teams they had been part of.

> *".. a really good, close team and dedicated staff. So it wasn't just the palliative care side, it was the uniqueness of the team and how they supported each other." Nurse 2*

Nurse four described reflecting within the team. Through sharing experience and knowledge the nurse is supporting her team members but also allowing themselves to make meaning of the loss and death of their patient. The reflection gives opportunity for the other team members to offer advice around symptom management and other issues for future learning but also support for the nurse following the death of the patient.

" I don't know if you've ever noticed but at a handover I'll go over a death, like, so and so passed away on the shift. I'll go over it. They were settled. They were this. They were quite distressed; could have done that, could have done this. I reflect without knowing I reflect which I suppose everybody does that but usually at my handover times that's when I reflect". Nurse 4

The support within the team for each other is an important factor in the dynamics and philosophy of care experienced by palliative care nurses. The nurse described the team as being like a family with the connotation of mutual support and respect for each other. It is important to feel part of the team and know that both professional and personal support is available.

"The team had issues within it and it wasn't really working , and I wasn't really getting any job satisfaction. So I returned to palliative care and I have remained there ever since…..kind of, like a family. I think you get a different atmosphere in these kind of areas " nurse 7

Nurse six when describing instances of traumatic deaths and their ability to cope emphasized the importance of team support. Talking to each other, to a team that understand their emotional thought process is important to the nurse. They acknowledge that it is a natural response to replay events over and over if the experience was traumatic but know that through mutual support and respect from their team members the impact of the event can be lessened and perspective given to their thought process.

"Yes, I think you can't help but think about it, it just goes around and round. Often with staff like whoever you are on with you sit and speak about it, and I think it just helps speaking about it, or you'll speak to whatever doctor is on the next day….I think it's important for the team that works there to know they can go and speak to somebody" Nurse 6

The type of training received by the nurses was also explicitly discussed in three interviews. The nurses described being trained up to "be professional" by " old school nurses" which implied being able to hide their emotions. They

felt they offered support and did not shy away from difficult or emotional situations. They conceded that a professional approach could be seen as showing a hard surface but they felt this was necessary to provide care in a manner in which the patient and family members needed. Reflection 15 presents the reflection of the researcher on their experience of showing a professional approach.

> " I feel empathy; I feel sad; I feel like I can do my job. I feel I've been trained up to an ability to be professional… I feel that I'm just doing, well, not a service but I feel like I'm doing something that they deserve. I've been taught in a way from quite old school nurses on how things should be, you know, like managing distress in patients and in relatives. Not taking a step back but them knowing that I'm there." Nurse 4

> "the best palliative care nurses are the ones that are like that, because you can provide that support. You don't crack under a lot of pressure. You don't get really emotional. You may see on the surface there's like an almost hardness I suppose, but I can see beyond that. To me the best nurses have been like that. When I was a junior nurse and a student I was really trained I suppose with a lot of old fashioned palliative nurses and they were like that, and that's, kind of, what's shaped me as a nurse." Nurse 7

Reflection 15. *Is old school the best approach ?*

The nurses discussed being trained by "old school" nurses and nurse 7 in particular describes a show of emotion as not being in control. Delivering palliative and end of life care is difficult with many layers of complexity which can result in anxiety and the emotional labour required to manage your thoughts and emotions in such circumstances can become overbearing. During the early part of my career whilst delivering end of life care I found it difficult to present as unattached and on occasion an inability to hide my distress from my colleagues if the death or circumstances were particularly distressing. As I became more experienced I understood that it is OK to be sad for the patient, their family and yourself. As a nurse you had a relationship which has been brought to a close by the death of the patient. I was able to support the patient and their family and allowed myself a period of reflection and sadness away from my colleagues. Often however a colleague will notice when a nurse is struggling and with a nod of the head or a knowing look will direct the nurse to take some time away from the ward to gather their thoughts. Nurses are often reluctant however to admit their feelings of distress to their colleagues if they regard the feelings as too intense. They sometimes see it as a failure to be professional and a reflection on their ability to deliver good quality care. They don't want to be seen as " not coping" and the nurse who becomes upset too easily. As nurses we should ensure we look for signs of distress amongst our colleagues as a healthy approach to understanding and supporting nurses who experience grief for their patients will ultimately benefit not only the nurse but the team and the organisation. As a result the care we deliver to our patients and their families will also improve and be sustainable. Grief and sadness are a normal response to loss and as a human being who is also a nurse I feel we must allow ourselves to experience emotions. The danger lies however in not being able to let the emotions pass, to enable us to continue delivering care to the remaining patients and also care of ourselves.

Intermediate theme - Permission to grieve

This intermediate theme emerged throughout all the interviews. Several quotes were of value in the analysis. The nurse admitted that they do grieve but are reluctant to show their emotions freely to the dying and bereaved as they see that as not being professional. They take their grief home with them and grieve in private. One nurse also said that they felt they were disrespecting the patients and families by openly showing grief. It was not their grief to have and they felt that would be somehow intruding on the patients and families relationship and intense final hours if they entered into their space.

> *"Quite often, I don't show my emotions here but I will go home - "I think that nurses they do grieve but maybe not in the same kind of level as families because we need to be professional. We can't engage emotionally in the same kind of level as families but we do." Nurse5*

> *"it's not your grief to deal with, you know, and I would never disrespect people by thinking it is…..."personally I couldn't do that every day if I was getting really, really, really emotional. I couldn't do it. So I think it makes a good palliative nurse." Nurse 7*

Reflection 16. *Is it Ok to grieve ?*

The assertion that it is not our grief to deal with took me by surprise. It felt as though the participant was admonishing nurses for experiencing grief for the patients or their families – as if they had "no right" to grieve. I personally had experienced a form of grief and had listened to stories of other nurses throughout this study who had clearly expressed sadness and grief at the death of a patient. I did not feel that I or the other nurses had disrespected the family by feeling sad at the death. I do understand however that we need to be able to support bereaved family members through their grief which would be very difficult if we as nurses appeared to be unable to manage our own emotions.

Nurse seven also discussed the importance of recognising if somebody was not coping with the grief. The inference was that they (the nurse) should speak to somebody about their feelings and could be seen as an indication that they could not cope and should not be in the position of caring for the dying as they would not be able to offer the care that was required and manage their own thoughts and emotions. Again the nurses admitted that they do feel sadness at the death but do not show their grief and prefer instead to hide it, not only from the patients and their family but also from their colleagues.

> *"I think if you recognised and you felt that anybody really wasn't coping (a) you would want them to talk to somebody that was actually trained to talk to them and (b) you would have to question whether actually it was the right place for them to be nursing."* Nurse 7

> *"but I think I'm quite good at just putting my professional head on- Sometimes I'll have a cry, I try and be as professional as I can and I have a wee bubble and then take a deep breath. I've done that a few times, but not – I often find I go home at night and I just think it over, like, I just think about it."* Nurse 6

Nurse six then became upset and started to cry whilst recalling the death of a patient. This nurse described the close relationship they had with the patient and their family and how the death impacted them. The patients daughters offered to collect rose petals from the patients garden for the nurse to use at her wedding in a couple of months time. The nurse still however did not want to show their emotion even though the relationship with the family clearly impacted them and endured after the death of the patient. It was not seen as professional to become involved but their innate sense of grief and loss was impossible to hide. The interview surfaced a great deal of emotion and possibly the nurse felt relief at being able to share their grief at the loss of a special relationship and friendship that had developed. There was a significant emotional burden experienced by the participant which required support. The nurse did not disclose if they did get any support from their colleagues but apologised for becoming emotional

and described themselves as stupid for becoming emotional. They felt that they should not be grieving the loss of the patient and certainly not openly displaying grief in such a manner. Reflection 17 describes the researchers response to the display of emotion during the interview.

> *"When she passed away her daughters brought in lots of rose petals after the funeral for me and stuff and, like, they gave me a card and, like, with a reply address on it and stuff. I'm going to contact them after the wedding – I'm getting upset again. - " Sorry, I'm being stupid."*

> *"She wrote me a little card with her address and that, so I always think of her and I think – sorry I didn't think I'd be like this. "* Nurse 6

Reflection 17. *Relationships and connectedness should be acknowledged.*

The nurse apologised for becoming upset almost as if it was a sign of weakness. I reassured them and tried to offer support even though the story had touched me and I became emotional also. I reflected on how the personal and professional can become so intertwined that it would be impossible to separate the two. Why should a person apologise for holding emotion and displaying sadness? Relationships with patients and their families can develop over time if the patient has spent a lot of time as an inpatient but equally strong bonds can form with certain patients or the families over a relatively short period. The nurse supports the patient and their family through a period which is often very intense and full of fear. A connection is formed and a therapeutic relationship develops. The nurse and those in their care are intimately entwined. When the connection is broken a feeling of loss is a reasonable emotion to experience and should be acknowledged.

Conversely nurse four stated that they did not show emotions when asked about experiencing grief for their deceased patients. This nurse spoke about their ability to stay detached from the grief and saw that as being

professional. They did question themselves however as they recognised that sadness was a natural emotion to experience after the death of a person but qualified this as way to cope and mange their emotions by seeing the bigger picture and understanding that they must remain professional and deliver good quality care in support of the patient and the family members.

> " It's made me think about me though, strangely enough. I find myself, I think I'm a bit hard faced in the terms that I don't let things get to me. I like to think I can see the bigger picture so I don't really…I don't find myself getting upset." Nurse 4

> " I never try and put myself in their shoes. I don't do that because it's not my grief. It's not me that has to deal with this. " Nurse 4

Nurse five discussed the value of reflection. Nurse number 5 spoke about the benefits of reflecting after a patient had died. They described the process they go through to make meaning of the loss and help them deliver care and continue in their role. They also mentioned how reflection helped them in their personal life as thoughts impact on emotion and this would also help in their professional role.

> "before I started studying I never thought that reflective is such a powerful way of learning. I never actually thought that is going to be such a useful tool for me but since I started to study palliative care actually I found it very useful. I didn't know about all sorts of different models of reflection and stuff like that but when I started to use it for studying I felt that reflection is such a powerful tool for me. It's not just about the work. It's about everything, I think. It's about even personal life..."   Nurse 5

Intermediate theme - Moving on

Six of the seven nurses discussed letting go and moving on to the next patient. They acknowledged that they do feel sadness but were reluctant to describe it as grief. They felt the depth and strength of the emotion did not warrant the label of grief but recognised that it is a basic human trait to feel sad after the death of a person. They recognised that they did feel sadness

but made a conscious effort to stop the emotion taking hold to enable them to fulfil their duty as a nurse delivering care to others.

> *"I think you have to be really careful but you're human and it's difficult to call it grief or sadness. I try to look at it…because if you go too in-depth then you will probably find yourself that you are grieving and you will then go through a process. So if I have a death, if I have a family, I'll look at it as a sadness, it is sad and try and halt it there." Nurse 2*

The nurse recognised that their grief differed from the family, they did feel sadness, sometimes quite a powerful emotion but had learnt to rationalise the grief and continue on with their care of other patients. They moved on from the grief and concentrated their efforts and emotions on caring for the next patient and their family. There was almost a sense of fear that if the grief was acknowledged it would overwhelm the nurse.

> *"But it's not like the family's grief that's going to go on for weeks and months. Yours is very short. I would say when a patient dies, it tends to be a short burst of…sometimes can be quite severe grief. You can feel…well you can feel the pain quite bad and it might last maximum a couple of days…two or three days. But then it's compartmentalised and you're on to the next." Nurse 3*

> *"I need to engage again with the other patients and I need to provide the care, the best care for other patients too. I need to move on and try to look at the other patients' needs and try to provide the care for the other patients. As I said, everyone is different. Every one patient is different, has got different needs so I need to focus on the other patients" nurse 5*

> *"it's hard to describe - you try and just that's your job and then it's, like, you just try and clean the slate and put on a new head for a new day kind of thing. " nurse 6*

Nurse seven conceded that on the surface an outside observer may assume that the nurse did not have an emotional attachment with the patient or their family. The nurse did however feel sadness at the loss but chose to stop the

grief becoming embedded because they need to do a job, they needed to care for the other patients on the ward and carrying the grief for each patient that died would not allow them to care for the remaining patients and their families in the way they deserved. The nurse also protected their own emotions to ensure that compounded grief did not become a process that they were plunged into.

> *"To the outsider looking in, you know, we come in, we'll look at the board and there'll be names not on that board that were on that board when you went off shift a couple of days ago, you know, and we just go, oh, oh, what a shame and then you just move on…I don't think you let it sink in deep enough. I think you, kind of, let it go so far and then it, kind of, stops and you don't really, sort of, let it sink any further, because then it maybe becomes more real." Nurse 7*

7.7.4 Superordinate theme 4. - Death anxiety and transference

The superordinate theme reflects the transference and anxiety around death the nurses displayed. Transference is experienced when feelings are provoked within a clinical relationship which are a consequence of the patients behaviour or state of being within a therapeutic context (Luban & Katz. 2016). Table 6 illustrates four intermediate themes, too young to die, standing in the shoes of the bereaved, it could be me and finally resilience.

Free coding	Intermediate themes	Superordinate theme
Young age difficult – relate to self.	Too young to die	4.Death anxiety and transference
Death anxiety linked to young age.		
Young age affects your emotions		
Difficult if young children involved		
Relate older patients to their own parents.	Standing in the shoes of the bereaved	
Putting themselves in the parents shoes – wrong thing to do.		
Personal experience of death and dying and wanting to improve care.		
Connection with patient or family		
Your child dying is every mothers biggest fear.		
Can be difficult to understand when patient knows they are going to die and accepting of it.	It could be me -I don't want to die	
Anxiety about not having children before they die.		
Try not to put myself in their shoes.		
Everyone is afraid of death		
A good death being surrounded by loved ones and dying alone is sad.		
Question if you could stay in PC long term.	Resilience	
Break needed so not too emotionally drained.		
The more experience of dying patients the better you become at dealing with it		
Need to normalise death		
Fear that to them death is normal.		
They don't worry about death		
Must be grief somewhere inside.		
Do question what its all about		
There can be positive aspects too.		

Table 6 Table of themes for " Death anxiety and transference"

Intermediate theme - Too young to die

The fear of dying at a young age was evident in six of the seven interviews carried out. The study was carried out an adult inpatient ward so the patients were all over 18 and the description of younger person could be described as any patient that had not reached en "elderly" status. Nurse one discussed how the young age of the patient made the job more difficult for them in particular. They felt the young person who had died still had a lot of life ahead of them, they felt that the patient must feel cheated that their life was been brought to a close. The assumption was that an elderly person had experienced a long and happy life. This may not have been the case but the nurse framed their assumptions within this understanding. In this way the nurse felt that the natural cycle of life had been achieved and everybody must die eventually, but only after fulfilling a long life. The nurses often associated with the age of the patients as they may have been within the same age bracket as themselves and felt that they personally had a full life ahead of them and the mortality of their patients impacted on them.

> *"I think sometimes it's difficult when it's a young person in my eyes".*

> *"I think obviously sometimes I think when they're elderly it's quite easy because you know they've had a good life and whatnot."*

> *"Maybe there's a young person who is dying so obviously the age factor is quite important too." Nurse 5*

Nurse six described her experience of looking after a patient who was young and had young children. The assertion here as that the young man had a young family and it was unfair that he should die and leave his family behind. The sadness was further compounded by the fact that the nurse knew the patient personally, outside a professional capacity. They felt the dying patient was one of their peers and made the death feel closer to them.

> *"and I just found that quite upsetting and stressful to deal with……The man he was only in his forties as well and I knew him as well – like I recognised him, so that I think got to me also"*

Nurse seven was asked about her emotions at the moment of death when they were present and looking after a patient. The nurse described being able to manage and control their outward appearance of emotion even if they felt a deep loss and sadness. They described a surge of emotion which was beyond their control but by suppressing the outward signs of the emotion they felt they had delivered care well to the patient and the family. They qualified this by saying they were "good" at hiding their true emotions. The exception to this was when they were faced with younger patients and particularly very young adults. They admitted that they struggled with the death.

"there are occasions where I've been with relatives and I do get a, kind of, surge of emotion and I think, oh, my goodness, but I'm quite good at controlling it - The ones that stick in my mind, we had a young girl that passed away and I found that really difficult"

Intermediate theme - Standing in the shoes of the bereaved

Four of the nurses in the study discussed the tendency to relate the dying patient to their own family members or loved ones. One of the nurses associated the patients with their own parents, one associated with another family member and two nurses associated with their children.

Nurse one discussed relating the patient to their own parents when describing how the age of the patient affected their grief reaction to the patient's death. The realization that their parents are possibly becoming older and frailer made the nurse think about their own parents mortality and that death is a part of life which affects everybody. The nurse seemed surprised at the revelation which presented when they started to care for and think about the patient they saw in front of them. The association became apparent and caused some discomfort to the nurse with the realization that their own parents would one day die.

"Then sometimes when it's maybe your parents' age you sometimes you start to think about your mum and dad and thinking, oh. " Nurse 1

Nurse five described how the death of a close family member impacted on them and influenced their career choice to become a palliative care nurse. In the previous quote the nurse reflected on how the patient reminded them of their own parents but in the following quote the nurse described how their own experience of loss of a family member influenced their career. They could empathise with the patient and the family members because of the experiences the nurse had lived through. They had undergone a similar journey and could offer support and care to the patient and family from a place of knowing. They did this in the hope of easing the burden of grief for all concerned, including themselves.

> *"Plus, probably because in the past I lost my ….and I know how difficult it was for my …. to actually to deal with his death. I felt probably lots and lots of different ways how we can change the system …. and how she could be treated to have a better bereavement time. I felt that was quite raw still for me and I felt that ..putting everything into the wards was much nicer. I felt that actually giving palliative care and preparing people for death, even the family is quite, maybe not easy task but is actually very useful for the people who are actually left on their own after the person is going to die."*
> *Nurse 5*

Nurse seven describes the fear of losing your own children. The nurse openly expressed their biggest fear of losing their child. The nurse could understand and process the patient's death and felt able to deliver care, however the patients bereaved mother caused the nurse to feel pain as she grieved for her daughter. The nurse imagined being in the same position as the bereaved mother and found this a very uncomfortable thought.

> *"because she was probably at an age of my girls. And it wasn't actually her dying that really got to me, it was her mum. You're trying to empathise because you can only just...you can't imagine at that point what they must be feeling, because I think it's every mum's biggest fear, isn't it?" Nurse 7*

The nurse then went on to describe another situation where a mother had lost her daughter. The nurse illustrates the internal battle to remain strong

and offer care and support to the dying and bereaved whilst managing their own negative thoughts and emotions. They feel it is their job to deliver care and offer support but must do so sometimes to their own cost. Nurse 2 also spoke about the difficulty caring for the dying who had young children and the different dynamic imparted on their relationship with the dying patient and their own grief around that loss.

> *"you're trying to be really supportive and things. But actually, in your head at the time you're thinking, oh, my God, imagine if this was me." Nurse 7*

> *" the ones that have (had a negative impact) are young children." Nurse 2*

Nurse seven also discussed generally associating with the dying or bereaved. They spoke about imagining themselves in that position, either dying or grieving. The nurse spoke about a connection or relationship which fostered the association with the patient or the bereaved, though they struggled to articulate why that connection happened.

> *" It doesn't happen very often and it tends to happen...I don't know why it happens. Whether it's because I've got a connection with the relative, or a connection with the patient, or it's reminding me of something. " Nurse 7*

> *"A lot of the time I think you're trying to imagine what you would feel like if that was you, either sitting at the bed or in the bed." Nurse 7*

Nurse two also describes how after a period of reflection following the death of a young patient they identified that they had experienced transference with the parent of the deceased. The nurse acknowledged the grief of the bereaved children and the anticipatory grief of the dying patient. They struggled when they imagined themselves in the patients position leaving behind children. They felt this was the wrong thing to do as it should all be about the patient and their family. They understood that they did relate to the similarities of themselves to the patient but did not allow themselves to

feel sadness or concern for themselves. Everything should be focused on the dying and bereaved.

> *"but only when I reflect back it's more putting myself in their shoes and thinking of my child. So it's not for their grief, it's more putting myself, you know, in their shoes and looking in it as if it was me- So that's the wrong thing to do, you can't do that, because it's more…because it then becomes more your feelings and not really about them. You're taking their situation to you and you shouldn't be doing that, you know, but you sometimes do because you can relate."*
> *Nurse 2*

Reflection 18. Furnishing their grief with our care

At the time of collecting the data I had not experienced a close relative dying and the grieving processes I had undergone after the death of an aunt or uncle had been a positive experiences in so much that the process and rituals undertaken around mourning were a celebration of a life well lived. After completing the interviews both my Mother and Father died and caring for the dying and deceased after those events became more painful for a time. I encountered the same inward dialogue of not wanting to "take their situation to me" but realizing that it was inevitable because I could relate to the bereaved sons and daughters. Some participants in the study also described their understanding of the grief experienced by family members due to their own experiences of loss.

I felt – *"I know what your experiencing, I want to help, but I must stay professional"*. As nurses we can still help, we can furnish their grief with our care and through support, help the bereaved at the time of the patients death. I felt my personal experience of grief added depth to my understanding of the process the bereaved were undergoing. By being truly present I was able to offer a blanket of compassion and truly be with the dying and bereaved.

Intermediate theme - It could be me - I don't want to die

This intermediate theme is concerned with the issue of transference between the nurse and the dying patient. Two nurses discussed their feelings around death anxiety without being explicit and two nurses openly discussed being afraid of dying.

Nurse one described how they felt when they had a patient who was approaching death before the nurse was due to be away from the ward for a period of time. The nurse expressed that they was afraid of dying and stated that they were too young to die. They found it difficult that the patient had accepted death and appeared so matter of fact about their forthcoming death and was in fact wishing it to happen. The nurse could not imagine anybody wanting to die. The patient died on the nurses birthday which appeared significant to the nurse.

> "When the patient feels that they're ready to die and they're accepting of that that's sometimes quite a strange thing as well. I had a patient who I said to her, now, I'm going on holiday, and I looked at her and I thought she's not going to be here when I get back. She actually turned round and said to me, well, I'll definitely not be here when you get back. She said, well, I'd blinking better not be. She said, I don't want to be here in a fortnight. That was like really…I found that quite difficult that the person had accepted that she knew she was going to die and she'd accepted it and she was like that, I know I'll not see you again and she died on my birthday when I was off - Maybe I think that I'm too young to die and I couldn't physically get that into my head but she was obviously a bit older than me."

> *Nurse 1*

Continuing with the theme of not wanting to die at a young age and being faced with death on a regular basis nurse 1 described how they were afraid of dying and did not like to think about it. They faced dying patients and death often stated that they dealt with it and managed well but avoided thinking about their own mortality. They also described the loss of future self for the dying patient and imagined the patient wanting to have children but

being unable to. The nurse may of been putting themselves in the shoes of the dying patient as they themselves had future unmet goals and life plans. They also repeated the assertion made by other nurses in previous quotes that patients of an advanced age had led a long and happy life and were ready to let go. This is obviously not true for all patients but the nurse built a picture of a life well lived and acceptance of the dying elderly. To witness the death of a younger patient closer to the nurse presented the nurse facing their own mortality which they found very uncomfortable.

> *"To be honest it's a bit mental but I'm scared. Some people say they're not scared but I think it's probably because I'm not even 40 years old yet and I'm faced with all these things every day through my job and I manage it and I cope well with it but you don't want to think about it for yourself. It's like, aye, I'm too young."* Nurse 1

> *"They've maybe not got any family, like children or they wanted to have children but couldn't because their cancer came. I think maybe with older people they've had their family; they've had a nice marriage and they're 70 or 80 and they're like, right, okay, I've had a good life. I think it is when they're maybe at the same age group as me where I think it can be difficult, definitely".* Nurse 1

Nurse five also equated a good death to being surrounded by family and friends and the patient dying alone caused sadness for the nurse. The nurse assumed that a good death meant being surrounded by family or friends and dying alone would not be wanted by patients. They felt sadness that the patient had nobody to share their final hours and minutes with and would try to ensure that the patient did not die alone, through being present with the patient. A younger person dying alone caused greater distress to the nurse.

> *"So if the patient was very peaceful, comfortable and we knew that the patient was surrounded by loved ones that's alright because we know that we've reached their wishes."* Nurse 5

> *"So probably when we've got a patient who has got a good circle of friends, who has got a big family, surrounded by their family,*

good friends during this difficult time is probably easier for the patient and for us because we know that they are not on their own."

"on many occasions it's happening that we've got just a single person. They don't have families or their families are scattered or there are different circumstances, maybe they don't speak to each other and they are just on their own." Nurse 5

"If it's a single person who is dying very young, doesn't have anyone, obviously it's going to have a huge impact on the nurses and the nurses will grieve more than looking after probably elderly person who had their life and they had lots of family and lots of friends around their bedside at the time of death." Nurse 5

Nurse four explained that everybody is afraid of death and they felt it was their role to make the journey towards death as calm and peaceful for everybody, patients, loved ones and nurses. They wanted to normalise the process and take away patients and loved ones fear.

"We think that we are that scared of death but yet it's quite a normal process that I like to think if I keep it together people won't be scared. " Nurse 4

"It's a way of life and it's always something that happens. You can't ever take away from it but we're all quite scared of it so I think to respect people we need to support one another at a time like that. It's a dying process and you want people to, not relax, you know, like it's a grief process. It's the start of the grief process but you just want people to have a good experience." Nurse 4

Reflection 19. *Providing support for others whilst navigating our own emotions*

Death is normal but it is also the last taboo. People are generally scared and reluctant to discuss death and dying. They may not have witnessed anybody dying or conversely experienced a difficult death. I feel, as this nurse, that we as palliative care professionals are tasked with forging the path to allow the dying to complete their final journey safe in the arms of our care and help to normalise the process as death is part of life. We must provide support for the dying and deceased whilst navigating our own emotions and feelings of loss or grief. We must remain strong but can not help being touched by the stories and experiences encountered as part of our care delivery. We try to take away the fear and in so doing allow ourselves to feel that we did the best we could to allow the patient to experience a good a death as possible. This gives meaning and context to our role and eases the burden off grief we potentially may feel.

Intermediate theme - Resilience

This intermediate theme of resilience arose from the ability of the nurses to manage their own thoughts and emotions in relation to death anxiety and transference. Every nurse interviewed discussed the concept of resilience without necessarily being explicit in the description of resilience in relation to dealing with death on a regular basis.

Nurse one was asked about their grief for patients when they had died and if they thought nurses did experience grief. They described how they tried to deliver care and "just do their job". They did however acknowledge that they were quite early in their career and that their resilience may not also be as strong. They described their heart breaking when dealing with dying patients on a longer term and needing to try and "fix" people to mitigate their feelings of loss and sadness.

> *"I just get on with it. Generally folk just get on with it. I'm here to do a job and maybe…I've been doing this for three years, maybe give us another couple of years and I might think, no, this isn't for me.*

I don't want to do this forever. It's breaking my heart. I want to go back to getting people better and trying to fix them." Nurse 1

Nurse two was asked about their desire to remain working in an acute palliative care ward. They discussed the difficulty in maintaining their desire and passion to work in the area. The emotional burden also impacted them physically along with the understood description of a physical burden.

"… emotionally and physically I don't think you can and I'm finding that out after … years. It's quite hard." Nurse 2

"Because of the emotional drain it affects you physically too. You know, the consistency of the emotional drain all the time and sometimes the work can be quite physical too. So yeah, it affects you both ways." Nurse 2

Nurse six also reflected on the impact of the job on the nurse after a long period of time. They described feeling content and happy that they had delivered good care to somebody approaching death but reflected that they were not sure if the work caring for the dying had affected them on a deeper level.

"It's just nice when you, like, especially if you get a patient who has come in from home and they've had a lot of symptoms, or if they've come from the other ward and being able to get them comfortable and, like, doing whatever you need to do to them. Then, it's just that's what I like about the job" Nurse 6

"I think – you do forget, like, what you do and, like, I sometimes wonder if it affects me, like, because you don't try and think about it. Then yes, you wonder if it does but - yes, I'm fine, I'm fine, but yes you just wonder, like, doing this for a while." Nurse 6

Nurse three works predominantly in the acute palliative care ward but occasionally rotated to other areas. They described the rotation as a welcome break from acute palliative care nursing. They recognised that dealing with dying patients on a regular basis had an emotional cost to the nurse. They welcomed the break away from caring for the dying and felt better able to cope once they returned to the acute palliative care ward.

"I prefer the palliative care to any of the other nursing that I've done. I still quite enjoy the … nursing and I think I'm quite lucky that you'll rotate like that. You get a wee break every now and then… But it's quite good to actually get away for a complete break just every…just to recharge the batteries" Nurse 3

"you get quite intense spells where there is a lot of grief and there's a lot of sadness and there's a lot…you've had a few deaths or there's been bad deaths" Nurse 3

"The bottom line…if you're dealing…if you're only dealing with something maybe once every two or three months rather than every two or three days, the more you do something, the better you get at coping with it." Nurse 3

Nurse four was asked how they managed their resilience to stress and anxiety in relation to delivering end of life care. They described how they became the stable rock in a distressing situation. They supported the dying patient and the bereaved by creating a calm peaceful space. They normalized death and dying. By being the calming force themselves, they helped to control the distress and anxiety in the situation and promoted acceptance.

" I like to think I'm calm and I think when there's one person that's calm in a situation others lock on to it. So if I'm calm I like to think that when you're calm it makes sort of everybody else quite calm or there's one person in the room that's calm. I think because it's such a distressing time, like that lady, I just put my arm round her, cuddled her, just supported her. I like to make sure that people know that it's quite, I use the word normal a lot because it is quite normal. I like to make sure that everything's happened in a normal pattern, if that makes sense, you know, death. I'm really into health promotion and it's the palliative care health promotion. We think that we are that scared of death but yet it's quite a normal process that I like to think if I keep it together people won't be scared. " Nurse 4

Conversely nurse seven questioned if seeing death as normal was acceptable. They described the frequency of caring for the dying within their role as a process which normalized death. They conceded that death should be seen as normal but their connection and involvement with the dying and deceased was not normal. They wondered if working in field of nursing that did not entail caring for the dying would make a difference to how they felt about things generally. They say they do think about death and the frequency they deal with the dying but do not worry about it, however the quote would point to a deeper concern around their attitude to caring for the dying and the impact that had on their everyday life.

"I sometimes think, is this a job that you should do for the whole of your career, because that becomes normal, that's normal to me. I think about that all the time. I don't dwell on it. It's just a part of my life and I do think about it, and sometimes I think to myself, I wonder if it would make a difference to me if I didn't have that in my life every day and would that be, like, quite refreshing, because it's not normal. Death is normal, but to experience death as often as we do is not normal. You know, it isn't normal. But because I've done it for so long it is normal to me, so I do think about it. I think about it, but I don't worry about it. " Nurse 7

The nurse then went on to state that all nurses worry about death deep down and transfer on to the patient.

"most nurses, nurses worry about, sort of, deep down worry about, oh, what if that was me? And you do, and you get something and you think, you know, you didn't get something simple, everything's..but that's, like, just being a nurse, that's normal." Nurse 7

"I just think, oh, that was sad, but then I get on with my life. But even that I find sometimes bizarre, because most people are, like...that's quite abnormal to...if they hear somebody's died they're quite shocked. But I don't get like that any more and sometimes I think it's that...I don't know. I think that's quite a strange way to be I think." Nurse 7

The nurse then acknowledged that they do feel emotion and empathy when a patient dies. They try to block the grief and try not to get too emotionally attached. They go on to describe how they think about their patients dying all the time and the unfairness of life.

> *"I don't think you let it sink in deep enough. I think you, kind of, let it go so far and then it, kind of, stops and you don't really, sort of, let it sink any further, because then it maybe becomes more real."* Nurse 7

> *"it is sad and you do feel for them and you do sometimes wonder what it's all about. I do all the time, because there's no rhyme nor reason and it's just unfair, but that's the way it is, isn't it, you know."* Nurse 7

Reflection 20. *Why study and research death and dying ?*

Nurse seven stated that death is normal but to experience death as they did is not normal. They didn't feel shocked at hearing about death anymore and questioned if that in itself was "normal". They then went on to ask what is it all about - two possibly opposing views the nurse shares and reflects upon. This brings the question to oneself – why study and research death and dying and grief and sadness? Initially it was a way to foster my own resilience as I felt, as many of the nurse in this study, that it was not professional to show grief openly and I must become more resilient. On reflection I know that death is normal and that nurses delivering palliative care experience death more often than nurses in other areas. Therefore experiencing loss and sadness in relation to death in a professional context is normal. Being resilient however does not have to include suppressing feelings of loss or grief.

Nurse two described the benefit of reflection and how this adds to their resilience. They try to find positive things for the patient and their family and concentrate on the difference they can make to the dying patient and the bereaved. They feel empowered by providing good quality care and support.

> *"it's in a sense empowering you too, just looking at it, not just everything's negative and, yeah, it's a death, but the positive way forward. I think we're good at doing that too. Because there's a lot of sadness and…not negativity, but sadness in death, but we try and bring out the positive in that as well."* Nurse 2

7.8   Chapter Summary

This chapter presented the findings which resulted from the analysis of the interviews carried out with the participants of the study. Field notes and reflective accounts were used to triangulate the interview data. The relationship between the participant and researcher prior to the research being carried out and the researchers experience of working as a palliative care staff nurse in an acute setting added context and depth to the analysis. The interviews were transcribed and subjected to IPA allowing a deep level of analysis. The researcher provides meaning of the meaning and therefore the findings presented are a result of the researchers perspective and own insight into the experiences of the participants within the study. The themes which emerged were the importance of being, the altruistic self, separating the personal and the professional and finally death anxiety and transference.

Chapter 8 will discuss these findings further. The discussion is set within the existing literature with the aim to meet the aims and objectives of the study, and in so doing suggest a framework in which an illustration of professional grief for palliative care nurses delivering care in an acute setting can be illustrated. The chapter will draw the findings and themes together to present a holistic view of the lived experience of professional grief that palliative care nurses experience whilst delivering care in an acute setting .

Reflection 21. My findings tell a story

As I conducted the analysis on the transcripts using my field notes and reflection a story started to emerge. The insights from the participants started to paint a picture of the compassionate nurse providing support and being with the patient. Their altruistic tenants were discussed and held up as a testament to the quality of care they aspire to. As the interviews progressed however the analysis identified further themes of difficulty in separating their personal and professional life. They are starting to explore their professional grief and share their insights around doubting their ability to cope with the grief. The complexity of their thoughts and emotions builds and climaxes with the fourth theme of death anxiety and transference. They were sharing their emotions freely and exploring new emotional territory which brought them to a potentially fragile and vulnerable place which they may not have dared visit before. I felt I reached the truth of the matter as described by Moran (Moran. 2000). An anti-traditional style of philosophising had taken place and the phenomena had revealed itself from within the participants.

Chapter 8
Discussion

8.1 Introduction

This chapter explores the findings and offers discussion around the themes and connections therein. The aim is to re-visit the original research questions that this thesis sought to answer to explore and understand the lived experience of professional grief that palliative care nurses in an acute setting experience whilst delivering end of life care and care after death.

1.   What are the experiences of palliative care nurses working in acute settings which underpin their attitudes to death and dying?

2.   What is the palliative care nurse's response to the loss of a patient when working in acute settings?

3.   What is the meaning of loss and death experienced by palliative care nurses working in acute settings after the death of a patient ?

The literature discussed in chapter two highlighted the relatively new understanding around the discipline of palliative care. No literature was found to highlight a theoretical understanding of the grief experienced by palliative care nurses working in acute settings. To this end literature around characteristics of the palliative care nurse and theories of professional grief were examined in order to draw parallels between available knowledge base and the findings presented in chapter seven.

The findings were presented as four superordinate themes which emerged from the intermediate themes and are presented in figure 9. which illustrates the building blocks of the intermediate themes which contribute to each superordinate theme. Each superordinate theme will be discussed in turn, with further detail around each component part of the intermediate themes to provide context to the overarching superordinate theme. Theses will be reviewed in light of the evidence which has been refreshed post study.

Figure 9 Presentation of themes around nurses grief

8.2 Discussion of superordinate theme 1. The importance of being

Free coding	Intermediate themes	Superordinate theme
Just being there – showing respect.	Showing respect to the family and knowing when you are needed	1. The importance of being
Just stood there with her in silence		
Not just a nurse	You are a person not just a nurse	
Important that they trust you		
Important they know you are there		
A lot of it is listening - Being there		
They see you as a real person		
Being there for people when they die.	Just being there	
Sitting knee to knee , just being there.		
We have to take a step back.		
Importance of being there		
Communication not always words		
Spending time with the patient		

Table 7 Table of themes for "The importance of being"

Cicely Saunders conducted extensive work on developing and improving end of life care. Through her work with the hospice movement she challenged the accepted views of healthcare professionals to examine how they delivered care. She identified the act of 'being with' as an opportunity for the nursing team to help patients face the anxiety of death and dying. This philosophy of care, with a new way of approaching care at end of life required close involvement of the nurse and a willingness to accompany the dying through their emotional journey (Saunders. 1984). This study identified very clearly the inherent values, knowledge and understanding of the nurses which are core to supporting and upholding this view of palliative and end of life care in particular.

Providing nursing and personal care for patients without investing time for meaningful exchanges could be argued as not constituting specialist palliative care which requires additional investment from the nurse (Haraldsdottir. 2011). The nursing team should be given opportunity to seize

the moment and be with the patient to enable them to contextualise their nursing care and focus on the needs of the patient (Haraldsdottir. 2011). This study clearly demonstrated this assertion and the participants in this study incorporated the act of being into their care delivery.

Most of the participants interviewed in this study referred to the philosophy of care within a palliative care setting and the importance of being there for the dying patient and their loved ones. They believed that when working within the field of palliative care they were able to provide more time with the patients and their loved ones and this gave them a sense of making a difference to the care they gave. The nurses frequently struggled to describe clearly what "being there" meant. To them it was symbolic of the principles of delivering good palliative and in particular end of life care, including an ability to identify when the patient and loved ones need the presence of a nurse. This presence was not to deliver invasive medical or nursing procedures, rather an understanding by the nurse of the need for compassion and empathy as and when the situation required. Just being there as another human being and sharing the journey offered solace to the dying and bereaved. Three intermediate themes emerged which were respect, you are a person not just a nurse and just being there. These are explored further in the following discussion.

8.2.1 Intermediate theme - Showing respect to the family and knowing when you are needed

Respect emerged as an important consideration among all of the participants. Showing respect to the family and knowing when to intervene was raised in several of the interviews. This appeared to stem from the nurse's perception that their role throughout the dying process is to support the patient and the family. In practice this means being with the patient and family. An awareness by the nurse of the dynamics surrounding the patient and their ability to assess the situation is critical. There is a fine line between offering support through being with the patient or loved ones and encroaching on the intimate space that the patient and their loved ones may need and want. A skill lies in recognising when the physical presence of the nurse it is not wanted or required.

The difficulty may also be compounded by the reluctance or inability of the patient or family to seek support from the nurse and they may not be able to invite the nurse in to witness or acknowledge their grief or bereavement. Therefore the "knowing" goes hand in hand with the "being". The issue of respect arises from the nurse's respectful quiet attendance at the bedside – offering support through presence alone and knowing how to interpret the situation and offer what is needed at the time it is needed.

Buckley (2008) discussed the importance of maintaining integrity and self-awareness for the nurse as a key to delivering good end of life care. Families and patient's needs should be considered at all times as misunderstandings and lack of awareness may lead to compromise and result in poorer quality of care according to Smith, Pugh and McEvoy (2012b) and knowing when the patient needs support is important. The nurse must be skilled in knowing when they are needed and invited in. The participants in this study understood the concept and importance of maintaining self awareness and the literature describes and supports their inherent understanding.

Self–awareness translated into practice through an example provided by nurse seven. When asked about supporting the families, nurse seven described that it was sometimes more important to support the family emotionally. A patient may need general nursing care that can be easily provided by the nurse, but the family may need emotional or spiritual support and may not be able to articulate how they feel or indicate that they need support.

According to Randall and Downie (2010) nurses have little control over the emotions experienced by patients as they approach death. However, they should try to understand their patients emotional state and thus show empathy which they define as being able to sense accurately and appreciate another person's reality, which will allow them to convey sensitivity. Halifax (2012) describes empathy as being affectively attuned to another person and is often associated with compassion.

Nurse seven also discussed how they believed the act of being with the patient showed respect, and felt this was important to the nurse, the family

and the patient. They also described how they understood that task orientated nursing was not always necessary or important as the patient approached death. They conceded that sometimes there was nothing to do at that time but "be there" for the patient and family and in so doing, allowed them to show respect for the patients deeply intimate situation. This reflection by the participant supported Randall and Downie's description of being able to sense accurately and appreciate another person's reality (Randall & Downie 2010).

All participants were invited to share their thoughts about the actual moment of death and how this made them feel. Nurse four felt she had grown more confident with experience. Initially she felt awkward, but over time, she learned to interpret each situation and knew when she needed to speak or not. She said that words are not always needed and communication happens in other ways. They inherently knew when support was required and were able to be with the patient and family.

Nurse four described a recent death where the wife of the deceased patient did not want to be alone, so the nurse stood quietly by – just being. They equated the act of being, of supporting the bereaved and respectful attendance with a peaceful death. Later in the interview the nurse was asked if experience working in palliative care helped in managing thoughts and feelings around death and dying and grief. The nurse replied that she thought it played a big factor not only in managing one's own feelings but in communication and confidence, knowing what to say and when to stay silent and just be a presence. Reflecting with the nurse on their earlier view about what to say and when, they believed it was important to recognise when these moments arise. For them, this skill was gained from observing other nurses and having the confidence in ones decisions at the time.

This approach and understanding of respectful attendance and being aligns with the assertion made by the Department of Health (2008) that a whole range of needs such as spiritual, emotional, practical and physical needs require addressing. The End of Life Care Strategy describes a good death as one where the patient is treated with respect and dignity. Where the patient has no pain or other complicated symptoms and being surrounded by

loved ones in a familiar setting (Department of Health. 2008). The nurses interviewed all described this strategy in action, and in particular elements needed to provide individual care with dignity and respect.

The nurses understanding of showing respect for the patient and the sacred space they inhabit was very clear throughout the analysis of the transcripts. The authors personal experience of being with a patient and their loved ones as death approaches and is imminent allows for a deeper understanding of the subtext of the nurses description of being with the patient. For an experienced palliative care nurse the knowledge that death is approaching is often more than a clear clinical picture but also a sense that the patient is preparing to die. Often the loved ones are aware of the changes taking place before them and look to the nurse for confirmation. Treating patients and their loved ones with dignity and respect is discussed in current literature but the interpretation of the discussions with the nurses in this study indicates a deeper level of meaning and understanding of the term respect. It is framed within a spiritual context and a deep connection and understanding.

8.2.2 Intermediate theme - You are a person not just a nurse

This theme emerged from four of the seven interviews. The nurses described wanting to ensure that family members in particular saw them both as nurse and a person; one that had feelings and emotions. They believed the two roles of the nurse and the person were intertwined and impacted on how they empathised and offered support at this time. Nursing is unlike any other job or health care profession as they have a close and sustained contact with the dying person and can positively influence the well-being of the patient facing death (Allen & Watts. 2012; Seymour & Ingleton. 2008,). The nurses in this study recognised this assertion and enacted it throughout their care ,but more importantly recognised the influence they could have within the care environment and delivery to the patient and their family.

Nurse one discussed their grief for the patient being unlike grief for a family member but conceded that it was sometimes difficult to hide the sadness.

They then went on to say that in the past they had been told that they shouldn't show their grief and emotions but they felt that showing a humane side in their view can comfort the family. In being present and with the bereaved they would be "seen" by the family and their presence would be welcomed and needed. Health care professionals often believe that their emotions and beliefs do not impact upon the care they deliver according to Doe and Katz (2016) as they perceive that it would not be professional to allow this to happen. They go on to suggest however that humanity and professionalism are not mutually exclusive and that this is no more apparent than when delivering care to the dying patient. The nurses desire to be "seen" by the family as they deliver end of life care would support the view of Doe and Katz.

In her opinion piece Rich (2005) states that in the first moments after a patient's death it is important to provide the bereaved family with sympathetic strength and understanding. From the assertions gleaned from the nurses in this study however the skill of the nurse lies in being able to support the bereaved family whilst maintaining the sympathetic strength described by Rich. The nurses in this study described being present but also showing support for the family and creating a safe space. They needed to be sympathetic but also show strength which was sometimes difficult to do.

Amenta (1984) described palliative care nurses as significantly more assertive, independent, forward thinking and less conventional than their counterparts in an acute setting. These traits may be the reason why some nurses believe that accepted norms for "hiding" grief are not the best way to proceed with care giving at end of life. Amenta's findings also revealed that hospice nurses are more likely to be deeply religious and have a high sense of spiritual significance. The religious aspect however did not emerge as a theme throughout the interviews conducted in this study although a spiritual significance was apparent.

The nurses in this study described how important it was to be visible to the family especially in the time leading up to the death. More time is spent with a patient approaching end of life as there is often uncertainty when the

patient will die. More attention is given at this time to support and reassure the family members, and in their view, families appreciated this.

They also described trust as an important factor between the patient and the nurse. They felt comforted that the family wanted them to be there as somebody they trusted not just a nurse. The family felt the nurse would know what to do and allow them to let go of some of their anxieties around the forthcoming death. Being a nurse was not the only important thing to the family in that moment. The nurse described their role and reason for being with the patient and family at that time were to provide truly holistic nursing care. However, the family had an extended need, they needed somebody to be there, a presence and somebody else to lean on.

Doka (2019) describes encapsulated identity where an individual behaves in a manner which is appropriate to the situation. The process however has three layers which are that the individual has to first define the situation. They then need to understand the aspect of self which would be appropriate for the situation, for example a kind compassionate person. Finally they seek validation of their behavior and interaction from those they are engaging with. Doka goes on to assert that the process can be complex and therefore can be unpredictable. The nurses in this study are aware of the need to read the complex situation at the time of the imminent death of the patient and become more than a nurse with the associated norms and expected behaviors.

Some of the participants of this study admitted that initially the act of communicating with the patient or family under such difficult and emotional circumstances was difficult but through experience they learnt to identify the need and benefit and were able to utilise the skill to support the patient and those important to them. To share the journey as a fellow human being. Doka (2019) suggests that interactions between people go more smoothly when each participant behaves in a way which is compatible with each other and there is mutual validation. The nurses in this study described a shared goal with the patient and bereaved and mutual validation of each other's role.

Nurse three also spoke about the importance of talking with and listening to the patient and their families. The relationship with the patient and family was being explored when the nurse stressed the importance of listening to the patient and relatives and being there for them. The nurse described how they shared a personal story of grief and loss with a family member on one occasion, which allowed the family member to discuss their own grief in a more open way. The role of the nurse was replaced by the role of a fellow bereaved person with similar feelings and experiences. The act of listening and being present in a capacity as a source of support as well as a nurse helped the grieving process for the family. The nurse was prepared to show their own humanity through an act of self-disclosure. They shared a common bond with the bereaved person. They also felt pain and sadness around the death of the patient.

Doka (2014) describes the bond that is quickly formed during a crisis event such as the impending death of a patient. He asserts that it is not surprising that the health care professional caring for the dying experiences grief but the early perspective was that they should maintain an emotional distance. Papadatou (2000) also describes how the health care professional may experience reminders of their own experience of loss or grief and this may challenge their belief as their patient dies. The nurse in this study however was able to draw on their own experience to form a bond with the bereaved.

Stayt (2010) in her opinion piece suggests that if the nurse has empathy with the patient or family then this may allow them to form a personal bond and engage meaningfully. Whilst nurses have described this as fulfilling there is a negative impact that they may experience a greater depth of grief once the patient dies. This view is evident in some of the findings from this study where participants described deep relationships with a patient and their family which led to a feeling of loss and sadness once the patient died.

8.2.3 Intermediate theme - Just being there

The importance of listening to and talking with the patient and their families or loved ones was a common theme which gave the nurses the opportunity to be with the patient and invest some of their own concern and care into the relationship. There may be occasions when the nurse can not moderate the

suffering of the patient or bereaved but through having the ability to be with the patient the nurse can provide assurances that they are not alone and provide the psychological and spiritual space for them to feel safe or supported (Arbore et al., 2016).

The nurses in this study described how they could meaningfully be present and connect spiritually with the patient and the bereaved. Communication and spirituality are intrinsically linked and presence or giving time to listen to the needs and wants of the patient and family contribute to the act of being there (McSherry, 2006). Appropriate responses such as comfort or touch, understanding and promoting self-worth allow the patients' needs to be met through the nurse being there and allowing the patient to be themselves (Sayers & De Vries, 2008). The act of being with the patient is described as a spiritual act in itself according to Puchalski et al. (2006). They also suggest that by identifying the patients suffering the nurse can offer compassion and dignity throughout a very frightening time. Nurse seven describes a physical and spiritual closeness to a bereaved mother where she sat knee to knee with the bereaved offering her support and comfort through presence and knowing rather than words of consolation or condolence. Through staying present and connected the nurse provided an opportunity for the bereaved to find the ability to respond to threat or fear with creativity and courage. A safe space is created in which the patient or bereaved can express a myriad of emotions including grief, fear, and desolation but also confidence, joy or even triumph according to Arbore et al. (2016).

As nurses delivering palliative care they felt that they were trying to forge a path through the uncertainty and provide a safe space which normalises death. This view was echoed by Becker et al. (2016) who reported that nurses delivering care to the dying in an acute setting in America described "providing a haven for safe passage" as a goal. The nurses in this study felt they offered support and comfort for the patients and their loved ones on their final journey through the gift of their presence.

8.2.4 Conclusion of superordinate theme 1. - The importance of being

The nurses in this study identified that being with should be initiated and invited by the patient or bereaved either explicitly or implicitly and therefore the "knowing" goes hand and hand with the "being". The issue of respect and dignity arises from the nurse's understanding that respectful quiet attendance at the bedside is required which can offer support through presence alone. However nurses should be given the opportunity to take the moment and truly be with the patient which is understood within a hospice environment but often difficult on a busy acute ward, as demonstrated by this study.

The nurses in this study understood that the act of just being there in the simplest terms could be described as the unspoken acknowledgement that the physical and emotional presence of the nurse offers sustenance to the patients approaching death or their loved ones experiencing bereavement. The nurses in the study enacted the situation whereby a mutually fulfilling relationship was developed with the patient or bereaved. The validation of the nurse as a person also supported the patient and the bereaved in a much deeper way.

They viewed their involvement as another person sharing the journey with the bereaved or patient - offering a compassionate and humane approach to the delivery of end of life care. Through physical and spiritual closeness to the bereaved, the nurse could offer support and comfort through presence and knowing rather than words of consolation or condolence.

8.3 Discussion of superordinate theme 2. - The altruistic self

Free coding	Intermediate themes	Superordinate theme
Felt they inherently could cope.	Inherent Values and a job well done	2.The altruistic self
Feeling responsible for a "bad" death.		
Making a difference.		
Palliative care more for them.		
Basic nursing care – holistic care.		
Inspired to work in PC		
People die in all areas		
Need to do a good job.		
Felt they could do the job and do it right.		
A good death then they feel OK.		
Own personality comes out – inherent way of caring – instinctive.		
a job well done.		
Support for patient and families.	Support	
Taking their worries away.		
Need to be prepared and in control	Being prepared	
Leading up to death feel anxious – want everything to go smoothly.		
Focus on being prepared for the death.		
Can be a blessing and feelings of relief when patient dies.	Relief after the death of a patient	
Relief when someone dies.		

Table 8 Table of themes for "The altruistic self"

According to Tschudin (1997) the word nurse originates from French and Latin for "nourishing". The nurse is viewed as a nourisher and healer and the nurses participating in this study provide nourishment in the form of care and support. Many nurses embark on a career in nursing as a result of a deep and unconscious desire to be nourished themselves and they gain fulfilment for this need through caring for others (Tschudin. 1997). Altruism is described by Puchalski and Gunther (2012) as dedication which goes beyond a job. They describe a key element of professional development

which is to recognise an inner call to embark upon a particular profession which entails service to others. They go on to say that our own personal identity is rooted in our chosen profession.

The act of being and offering a humane approach to care was entrenched in the nurse's philosophy of care. All the nurses in this study described values that included compassion and empathy and together these inspired them to deliver high quality and compassionate care. They felt responsible for ensuring the patient had the best death they could and felt they had "done a good job" if this was achieved. Luxardo et al. (2014) interviewed clinicians and found there were many rewards for working in palliative care. The first intermediate theme to emerge within the altruistic self was inherent values and a job well done. The second intermediate theme of support for the patient and family was very important in forming part of their approach to care for self and others. The third theme of being prepared was common throughout every interview. Finally, relief after a patient had died was the final theme and discussed by four nurses

8.3.1 Intermediate theme - Inherent Values and job well done

Inherent values and a job well done were validated by the feeling of doing good through helping others. The gratitude that ensued from the patients, loved ones and families was important to the clinicians and served to further their belief that they had delivered good quality care.

Many of the nurses described how they felt they inherently could cope with the demands of the role. They went on to explain how they did not become depressed after the death of their patient and therefore they saw that as an innate ability to manage the situations and their emotions that arose with patients and their families. Gerow et al (2010) describes how some nurses caring for the dying felt that they travelled through the experience as if being led by something which was outside their realm of knowing. This resonates with the assertions of the nurses in this study who just "knew" what was needed.

Nurse six described how palliative nursing came naturally to them and this gave them a lot of job satisfaction working in the palliative care unit. Other nurses described how they moved to other wards to gain experience but

moved back to work in palliative care as soon as the opportunity arose as they felt comfortable and connected whilst working in the palliative care field. Kirby (2003) suggested there were particular traits of nurses working in palliative care, describing them as individuals with the desire to care for others which in turn required commitment to reach out. These traits were demonstrated in the responses of the nurses in this study.

A deeper exploration of why these nurses believed palliative care suited their style of nursing or inherent values ensued. They described palliative nursing as looking at the person, their situation and family dynamics as the underpinning approach to care that appealed to them. They enjoyed delivering care in this way as things were not looked at in isolation and they felt this was very important. They described other experiences that they had on other wards as not living up to the philosophical approach or values of true palliative care, which could be described as needing to detach from the task of making the patient well and asses all aspects of the patients care and wellbeing.

Bradshaw (1996) states that care of the dying is "quintessentially" the essence of nursing as it is the time when nursing care is at its most important and fundamental. Bradshaw argues that an ethical ideal is fundamental to the compassionate and humane approach and delivery of palliative and end of life care. Dunn et al. (2005) conducted a study around Nursing experience and the Care of Dying Patients in America and found that the nurses reported having very positive attitudes towards caring for the dying and that they found the work worthwhile and important. Gerow et al. (2009) conducted a study examining nurses experience surrounding the death of their patients and described how nurses delivering end of life care felt they had been better nurses during the delivery of end of life care than they had ever been. They felt as if they rose to the occasion and went beyond the usual realms of nursing care because they were giving comfort to a fellow human being.

The nurses participating in this study echoed the assertions made by nurses in the study carried out by Gerow et al. (2009) through demonstrating a belief that palliative care enabled them to deliver good quality "proper"

nursing care and described the importance to them in helping people to manage their symptoms and dealing with other issues that might arise. Luxardo et al. (2014) suggests the main rewards for palliative care nursing included the nurse feeling good through helping others and in turn receiving gratitude from the patient and their loved ones. Some nurses found it difficult to articulate the difference between palliative nursing from other forms of nursing care but knew that they enjoyed working particularly in the palliative and end of life field. Nurse three described palliative care as something special but could not describe what the extra dimension was. They preferred palliative care nursing to other areas of nursing and the feeling of making a difference to their patients, which the philosophy of palliative care supports wholeheartedly. In contrast Mak et al. (2013) in their study examining the experiences of nurses caring for the dying in acute settings, found that nurses sometimes felt helpless and inadequate. They felt they had missed the chance to offer support to the patients as they approached death due to the task orientated approach to nursing in an acute setting and sometimes inflexible hospital policy.

Katz and Sidell (1999) assert that the emphasis on holistic nursing care in generalist nursing captures the essence of proper nursing required to deliver good care to the dying patient. The difficulty lies within trying deliver end of life care, underpinned by the philosophy of care inherent in palliative and end of life care, in a busy acute setting.

All the nurses interviewed felt their compassionate personality and qualities were demonstrated in their style and approach to nursing and described how they felt there were no right or wrong answers in palliative care, instinct was viewed as being very important and they inherently knew how to care for the patients and bereaved. Kirby (2003) describes palliative care nurses as possessing a deep moral source from within themselves which compels them to act in a compassionate way. Their altruistic nature meant that they gave freely of themselves without thought for their own feelings of loss or grief. Johnston et al. (2014) describes an expert palliative care nurse as having humane characteristics such as warmth, kindness and compassion. They have not only the ability but also the willingness to listen to the patient and their loved ones.

Most of the nurses described palliative care nursing as compelling and part of their make-up, something which they could not change about themselves - an inherent value which they had no control over. De Souza and Pettifer (2013) suggest that the desire to care for others is deep seated and fundamental and that people who go on to choose a career in a caring profession recognise and identify with this desire within themselves. They therefore try to develop skills through education and training to be able to deliver care in a professional context.

Corso (2012) in his opinion piece discussing oncology nurses working in America, describes the nurses as wounded healers and suggests that patients need more than a clinically competent nurse. They need a nurse at their bedside who can be the hands, heart and soul of compassion.

Nurse five was inspired to work in palliative care after attending training courses on palliative care delivered by a doctor in the field, whilst working as a general nurse. The nurse described how they felt inspired by the compassion and enthusiasm of the doctor to pursue further studies in this area with a view to undertaking a career in palliative care. They felt an overwhelming need to work in palliative care. Other nurses echoed this desire to work in palliative care and how they immediately knew that when a position became available on the palliative care unit they wanted to apply for it. They felt they could do the job and do it well – they felt they had the innate ability to perform the role of a palliative care nurse to a very high quality and this would result in a high level of job satisfaction. The overwhelming need to work in a palliative care environment discussed by the nurse sin this study echoed the assertions made by De Souza and Pettifer (2013) that the desire to care for others is deep seated and fundamental.

The nurses in the study wanted to make a difference to the quality of care and death experienced by the patient. The medical model of nursing holds a systematic and robust approach to care but misses a significant point in the views of the nurses in this study. The human aspect of care and nurturing of both the body and soul is fundamental in approach to delivering nursing care and palliative care allows this dimension to be considered and acted upon in a supportive way

The unit work style is an important factor in the system of goals, values and assumptions around the care of the dying according to Papadatou (2000). The work style is affected by and embedded in the institutional context and cultural environment in which the care is delivered. Each unit will have different definitions and interpretations around death which in turn dictate unique rules around how different team members behave and are expected to cope with delivering care to the dying and their own grief. The unit work style of an acute palliative care unit will be very different to that of a generalist or surgical unit, but also it is important to note that it will also differ significantly to a Hospice setting. The nurses described wanting to work in a palliative care setting or field and this may be because they identified and supported the work unit style within the palliative care field.

The theme of doing a good job appeared throughout the interviews and was linked very closely to the themes of innate ability and inherent skill. Nurse six described their feelings of frustration when they felt they fell short of providing high quality care to one of their patients or their families. It was very important that the job was well done in their eyes. This feeling of satisfaction of a job well done was a strand running throughout many of the interviews. They gained satisfaction when they had made a difference to a patient and their family and given them the best care they can. Strada (2013) uses the terms compassion satisfaction and exquisite empathy when discussing the deep sense of well-being and pleasure a clinician experiences when helping others and connecting emotionally with them within boundaries.

 The satisfaction the nurse's gained from delivering care to the best of their abilities and contributing to a good death were important factors in the coping and grief process which emerged from the information gleaned from the interviews undertaken. The study conducted by Mak et al. (2013) found that nurses satisfaction levels were increased by their own good practice. The nurses in their study perceived that through delivering good quality care themselves, their colleagues would be inspired to deliver good quality care which would in turn benefit not only the patient and their families but also the team as a whole. This point illustrates that nurses gain satisfaction from acting in the interest of others which is echoed in the responses gleaned

from the nurses in this study and describe the intermediate theme of inherent values and a job well done.

Distinguishing between personal and professional grief was an area explored throughout and linked to a job well done for some of the participants. Professional grief was described by nurse seven in terms of a job well done. If they had a lot of deaths or emotions to deal with in a short period of time but managed to deal with the situation and manage their own emotions, they felt the act of coping meant that they had performed well in delivering care. Nurse four described a situation where they experienced thirteen deaths in the unit in a two a week period. This nurse described how they usually coped very well with patient's death and felt able to offer support to the bereaved and carry out their nursing care to a high standard. The frequency of deaths and intensity of emotions which ensued however caused the nurse to become very emotional and upset at the time. The nurse offered an explanation for their perceived lack of coping, stating that the ward was very busy, they had resource issues and they were tired and emotional. They were relatively new to the ward and therefore had not experienced the intensity of numerous deaths in a short period of time previously. The nurse wanted to provide good quality care to the patients at the end of their life but felt that through time constraints and lack of resources they were unable to deliver this. They also stated that they were new to the ward and this would have impacted on the care delivered and their ability to cope. Mak et al. (2013) describes how junior nurses in particular felt that provision of quality end of life care is hindered by task orientated settings which made them feel helpless and insufficient if they were not able to deliver compassionate care with the time and space required.

 In a study seeking staff perceptions around end of life care, Marshal et al. (2011) noted that staff shortages and heavy workloads often leads to inadequate patient care and the clinicians experiencing frustration. Luxardo et al. (2014) echoed this when presenting their findings from qualitative research undertaken in South America to gain insight into Palliative Care Staff Perspectives. They found that some clinicians reported needing more time to deal with the demands of palliative care. The healthcare system was

described as hostile environment with lack of resources and an institution that was dehumanised. The nurses in this study discussed having time to care for patients and their loved ones and delivering good quality person centred holistic care but the reality is that on a busy acute ward, time and resources are often stretched which may lead the nurse to be dissatisfied with their perceived quality of care.

Nurse four encountered thirteen deaths in a short period of time and this number of deaths could present problems with the nurse managing their own feelings of grief and loss as they would be oscillating between degrees of loss and meaning making. After the death of a patient the nurse usually undergoes as period of reflection before moving on to care for the next patient, however if deaths come in quick succession the nurse may not have sufficient time to process the feelings around each death before encountering a further death with its own unique set of circumstances. The nurse would then be experiencing two different stages of reflection or coping simultaneously. Papadatou (2000) describes "private shadows" experienced by clinicians who care for the dying and experience multiple deaths. The concept is that the clinicians experience a range of painful scenarios where the feelings and emotions generated from these are hidden from public view. These shadows however are described as integral and unavoidable as part of care delivery. They also become part of the natural grieving process experienced by clinicians when facing multiple losses.

Papadatou (2000) however concludes that if clinicians and nurses recognise and accept their grief, sometimes with multiple deaths, they can find value and satisfaction in their work. In this study, the nurses reported that a perceived good death allowed to them to move on and let go much more quickly. They were able to derive satisfaction from their work which enabled them to face the next task ahead of them. Luxardo et al (2014) asserted that clinicians needed to "work" on their own perceptions of death and dying and reported how one clinician in their study stated that in order to help others in the dying process they needed to address their own mourning.

When talking about the death of a patient, nearly all the nurses equated a peaceful death with a job well done. Nurse six was asked how they felt when

they were with a patient as they die. The nurse described how the peacefulness of the death affected their own emotions. They went on to explain how a peaceful death left them feeling as they had done their job well and they did not experience a strong negative emotion. However, if a patient experienced a difficult death through pain or anxiety then the nurse felt responsible and did not feel they had done a good job. Watts (2012) reminds the reader that a prominent social and political priority is to achieve a good death albeit that the notion of a good death is a fluid concept. He goes on to assert that health care professionals strive to deliver care which will enable or facilitate a good death, but this intention may not always be straight forward. This view is supported by Luxardo et al (2014) who found that a good death equated to family support and dying in peace and relied much less on the physical attributes. The nurse may not be able to influence family support for example.

Nurse six then described how they became emotional themselves when a patient experienced distress approaching death. They described an occasion when they were crying with a patient's son. The son and the nurse together witnessed the distress experienced by his mother. The feelings of despair were very strong from the nurse and they felt they had let the patient and their son down by not being able to give the patient a peaceful death.

The nurse stated that they went home after their shift and cried at home that night and again the next day when recounting the experience. During this part of the interview the nurse became emotional and did start to cry again. The emotions were very strong and when reflecting on the episode, emotions were brought to the surface once again. The nurse discussed how traumatic the whole experience was for them and described it as the most traumatic thing they had to deal with.

Several nurses described their feelings of being responsible if a patient did not have a good death. They acknowledged that it was not always possible to ensure the patient died peacefully but they still became emotional and continued to be distressed by the situation even when they had finished their shift and left the ward. One nurse said that she felt useless when a patient experienced a bad death as they felt they had let the patient down and not

carried out their duties to a high standard. Strange (2005) implies that narratives around good and bad death are often misinterpreted as the complexities of process are often not considered when describing the event itself.

All the nurses knew that a difficult death did not equate to poor quality of care as symptom management can sometimes be very difficult. Terminal agitation of the patient for example, can cause great distress to patients and their families when the agitation cannot be managed medically (NHSScotland. 2014). The perception however was that the nurse should be able to do something to relieve this for the patient because of their innate desire to ease the suffering of the patient and their families. When not achieved this inability to act caused negative feelings. The concept of a good death however may vary between patients, families and healthcare professionals with the view that death can never be viewed as " good " for some people (Katz & Sidell. 1999).

As described in the previous paragraphs nurses often felt responsible if the patient did not experience a peaceful death and the resulting negative feelings resulted in the nurses requiring support and reassurance. According to the nurses in this study, support for them came from their colleagues and self-reflection. A report commissioned by Hospice UK (Goodrich. 2015) found that hospice staff need to be actively supported in order to reduce risk of compassion fatigue and reduce levels of stress. This would also improve job satisfaction. Within the report a framework was developed to help healthcare staff to provide compassionate, high quality care. One of the strategies for reducing and coping with stress was to ensure team leaders ensured clinical supervision was routinely in place. Restorative supervision and support for distressed and burnt-out clinicians should be available. Good team management would also ensure clear team goals were in place and facilitate team reflection. This would reduce the feeling of personal responsibility or ownership of a situation (Goodrich. 2015).

A study undertaken by Francis and Bulman (2019) also identified that a group reflective process and provision of clinical supervision did affect the development of resilience in hospice nurses. Confidence was developed,

emotions regulated and coping strategies were offered. They offer it as a recommendation for practice to enhance resilience. There were no studies identified throughout the literature search, which examined the use or relevance of clinical supervision for nurses in palliative care acute settings. Nurses delivering end of life care in acute settings undergo many of the challenges that hospice nurses face and experience similar thoughts and emotions whilst delivering care. The same recommendations should apply to this clinical group also.

Whilst this study was carried out in a palliative care ward in an acute hospital there are close similarities to the work undertaken and care delivered in a hospice environment. The research carried out for this study identified that clinical supervision was not routine or formalised for the nurses delivering palliative care in this acute setting, even though they had unmet needs and demonstrated signs of persistent grief. However, for nurses working in a palliative care setting where multiple deaths and dealing with bereaved relatives are the norm, then a similar approach to the framework developed by Goodrich (2015) would offer a good source of support. Worden (1991) suggests that health care professionals working with patients approaching end of life should know how to reach out for help and know where the support would come from. For this knowledge and understanding to be reached however the provision of clinical supervision and space for reflection must be readily available for all nurses regardless of clinical area.

8.3.2 Intermediate theme - Support for the patient and their family

The importance of support for patients and family members was a strong theme throughout all the interviews. The notion that they should go beyond the constraints of their role urged them to give the utmost support during very difficult times for the patient and their family. Nurse one described support for the patient and their family as an intrinsic part of their role and felt that support around psychological and spiritual issues underpin palliative care nursing.

They described making the patient and family members feel safe and nurturing the family unit by providing a safe space where they feel looked

after. In support of this view, nurse five described their desire to take the patients worries away. The nurse felt it was their responsibility to care and support the patient and family in this way but more importantly it was what the family deserved. Corso (2012) suggests that nurses understand that acknowledging and witnessing suffering is part of their work and try to understand each person as an individual to offer support unique to their individual needs.

Nurse four described a revolving door where anxiety from the patient passes to the family and back to the nurse and where the anxiety from the nurse if present has an impact on the family dynamics. The nurses felt it was their role to provide a calm safe space for the patients and family members - to give them peace and make them feel at ease. They did acknowledge however that this can sometimes be difficult to achieve. One nurse described trying to stay detached so that they did not get drawn into the emotional side and stayed focused on the patient and family's needs.

Peters et al. (2013) found that nursing is emotional work, not only because the nurses own emotions become involved when they develop relationships with their patients but also because they need to deliver care to a grieving family. This demands emotional maturity and they reported that some nurses use strategies to avoid discussing emotional factors with their patients or families and this resulted in emotional distance. The nurses who participated in this study however approached the support of the patient and family member as fundamental to the care they delivered. It was identified however that nurses delivering end of life care in acute settings also have their own support needs which were not often met.

8.3.3 Intermediate theme - Being Prepared

The importance of preparedness arose in six of the interviews. Through being prepared, particularly at the start of the shift they mitigated their feelings of anxiety leading up to a death. The nurses all ensured that everything was in place that needed to be, and in so doing contributed to doing the best they could for the patient and their family. The anxiety the nurse felt leading up to the death of a patient could be managed by being prepared and feeling in control of the situation. The nurses interviewed

generally felt anxious leading up to a death as they wanted to ensure they could meet the patients and families wishes and keep them comfortable as they approach death. They described how they check that everything is in place including anticipatory medication, updated notes and escalation plans together with contact details for next of kin. This allows them to feel prepared for any situation as they feel it is their responsibility to provide a good death. By preparing for all eventualities they are reducing their own anxiety.

The literature review that was undertaken did not identify many relevant studies examining the importance of feeling prepared leading up to the death of a patient when delivering palliative care in an acute setting. However, in their study conducted in the USA, White and Coyne (2011) found that some oncology nurses did not feel adequately prepared to offer good quality end of life care, and in particular around symptom management. This would cause distress to the nurse but they asserted that this could be rectified through supportive education programmes. The nurses in this study specifically mentioned symptom control as one factor they could influence and perceived this area as fundamental to delivering good quality end of life care. Powazki et al (2013) found that more mature nurses with clinical experience and further specialist education had a positive impact on self-perceived capability and comfort. Some of the nurses in this study were experienced and felt prepared because they had the breadth and depth of knowledge to provide good quality care. A clear finding from this study however which contributes to new understanding of nurses grief is the fundamental need to feel prepared.

Nurse seven compared the process of being prepared to that of solving a puzzle. They described having all the pieces that need to fit together to ensure the right outcome at the right time. There is an element of the unknown in providing end of life care and the nurse felt that they must be prepared for any situation that arises with the patient or the family. They felt that the patient and family being supported and cared for is their priority for the next few hours. Nurse four also approached the impending death of a patient with a strategy of preparedness. This gave them confidence to resolve problems as they arose.

Many of the nurses described how they ensured they always spoke to the families and patients who were approaching end of life when they started a new shift. This helped the nurse feel prepared for the death. By preparing the family and the patient for the approaching death, the nurse felt that they were doing a good job and delivering care to the best of their ability. In contrast to this Becker et al. (2017) conducted a study with 49 nurses who provide care for the dying in acute settings in America and found that some nurses expressed difficulty in talking to patients who were approaching death. The findings more accurately reflect an acute setting where the focus is on cure and not care and uncertainty around the unstable status or expected deterioration of the patient may present problems when communicating with the patient or family members. If the nurse is unable to communicate with the dying patient and their family around the imminent death then they are not able to prepare the patient and their family for journey ahead.

A lack of preparedness for a patient's death was a key concern for the nurses participating in the study conducted by Mak et al. (2013). The nurses experienced emotional and somatic impact. The setting however was an acute medical admission unit in Hong Kong and sudden and unexpected deaths were not uncommon. The nurses participating in this study deliver palliative and end of life care in an acute setting and often the diagnosis and prognosis of a patient are generally known and therefore the capacity for the nurse to prepare is much more evident. The constraints of an acute setting however should not be overlooked and this can and often does impact on the ability to adequately prepare for a patient's death. There are some similarities to be drawn from the study conducted by Mak et al. (2013) albeit in an acute medical admissions ward in Hong Kong. However there was no evidence found throughout the literature review of similar studies exploring preparedness for nurses delivering palliative and end of life care in acute settings in the UK. Through the research carried out in this study, it was identified that the nurses in this study also experienced somatic and emotional distress if they could not prepare or felt unprepared for a sudden acute event mirroring the results from Mak et al. (2013). A new finding from

this study is the distress the nurses face when feeling unprepared to deliver end of life care to a good standard in an acute setting.

The act of preparing for the death of the patient involves many levels not only practical but also emotional and psychological. This complexity of feelings and emotions compounds the uncertainty many nurse face whilst caring for the dying.

The nurses in this study identified the absolute need to prepare themselves, the patient and the loved ones to ensure a good a death as possible was achieved and they endeavoured to achieve a state of preparedness with which they felt comfortable.

8.3.4 Intermediate theme - Relief after the death of a patient

 The fact that a patient was no longer suffering, and the family did not need to witness any more pain caused feelings of relief in the nurse immediately after the death. Relief not only for the patient and their family but also for the nurse All participants were asked to describe the moment of death of the patient. Nurse one explained how they sometimes felt it was a blessing, especially if it had been a traumatic death for the patient and family. They were relieved for the patient that their suffering was over but also relieved for themselves.

Nurse seven also commented on the relief felt after a difficult death and the effect the death may have had on the patient, family and nurse. They describe the feelings of relief that the pain has stopped for everybody. Pain in this context referred to cessation of physical and emotional pain for the patient but also emotional distress for the loved ones and the nurse looking after the patient.

The nurse's grief following the death can be mixed with feelings of relief, which may be similar to those feelings experienced by the bereaved loved ones. Zisook and Shear (2009) findings align with this study whereby grief is not only about pain but may be combined with positive feelings of relief, joy and peace after the death of an important person. Whilst the description relates to grief experienced by loved ones it could be argued that the patient is an important person to the nurse also. Papadatou (2000) also recognises

that nurses may experience a sense of relief after a patient's death and understand and feel satisfied with their contribution to the care provided.

Nurse two agreed that the period immediately following a death held a lot of relief for the family and the nurse. Their own sense of relief came from the knowledge that the patient had had a good death, and they were personally able to deliver good quality care that was instrumental in contributing to a good death. This theme also links with the theme of *you are a person not just a nurse.* The nurse here is allowing their humane approach to surface and this impacts on their thoughts and feelings and points to an emotional investment by the nurse.

Kelly and Varghes (2006) concede that the anguish of watching a painful or difficult death can have an impact on the health care professional. They may experience a sense of relief when they learn that the patient does not have to undergo any further invasive treatment or that they have died. This view is echoed by many of the nurses in this study and supports the findings of their study.

8.3.5 Conclusion of superordinate theme 2. - the altruistic self

The need to nourish and be nourished is a fundamental tenant of nursing and the nurses in this study had altruistic tenants of having the desire to care for others which required them to reach out.

A good death was the ultimate goal among the nurses and they felt they had "*done a good job*" if this was achieved.

Nurses could experience multiple deaths in a short time frame and this may impact on their ability to manage their own emotions as they may not have sufficient time to reflect on each death before encountering a further death. The nurses all believed that support for the patient and loved ones was an intrinsic part of their role and wanted to create a safe space for the dying patient. The study identified however that the nurses themselves have unmet needs and experience persistent grief with little or no formal support. A further important finding was that a feeling of being unprepared for the death added to the nurses emotional distress.

The relief that is sometimes felt after a patient died extended beyond the feelings of the loved ones to include the nurse delivering end of life care. The cessation of pain and anxiety for the patient and distress or anxiety experienced by the bereaved and the nurse was welcomed, as the patient was finally perceived to be at peace.

8.4 Discussing superordinate theme 3. - Separating the Personal and Professional self

Free coding	Intermediate themes	Superordinate theme
Relationships are formed and do impact on you .	Relationships and connectedness	3. Separating the personal and professional self
Conflict of being "professional" and developing relationships with patients and families.		
Difficult when looking after somebody you know.		
Relationships affect how you feel about a death.		
Last respectful thing I can do.		
Good close team is really important	Teamwork and support	
Support colleagues through group reflection.		
Best nurses don't get emotional – trained by old school		
Not professional to show grief but admit that they do get upset	Permission to grieve	
It wasn't nurse's grief to deal with and wouldn't disrespect family by assuming that it is.		
Good PC nurses don't show emotion.		
Question themselves – too unfeeling?		
Importance of reflection.		
Describe it as sadness not grief – call a halt to grief.	Moving on	
Short burst of grief – move on to next patient.		
Need to move on to look after the next patient the next day		
Clear your head – new slate then move on.		

Table 9 Table of themes for "Separating the personal and the professional"

If altruism is dedication, which goes beyond a job and our own personal identity is rooted in our chosen profession, then it is understandable that palliative care nurses often face difficulty in separating the personal and professional beliefs and values. All the nurses discussed the duality of their

role and emotions throughout the interviews. There were four intermediate themes which emerged. Following on from the theme of the altruistic self the first theme emerged as the concept of relationships and connectedness with the patient and loved ones. The second theme of teamwork and support influenced their perception and their ability to perform well in their role and gave them a sense of a job well done. The third theme of permission to grieve appeared as the notion that it was not professional to show emotion or grieve openly for the patient. Finally the assertion that to be able to continue giving good quality care to the patient and loved ones and manage their own emotional wellbeing the nurse had to let go and move on emerged as the fourth theme.

8.4.1 Intermediate theme - Relationships and connectedness

Papadatou (2000) suggests that health professionals do invest their relationship with patients and their families but to varying degrees. The investment includes the professionals goals and interventions, their aspirations and their professional identity and role.

Nurse one described having a "big" relationship with their patients, giving weight to the importance of the relationship by describing it as big. The investment in the relationship by the nurse left them open to experiencing pain and sadness when the patient died. The nurses mitigated their feelings of sadness or loss by through personal reflection. The feeling that they had given the best care they could as the patient approached death gave comfort to the nurse.

 Nurse three and five described how their relationship with a patient and the closeness was directly related to the time they were in the clinical area with an attachment and close bond developed by both parties. With some patients, there was a stronger attachment, and this attachment extended to the family members or loved ones especially if the nurse had frequent contact with them also. This view is echoed by Papadatou (2000) who agrees that a special bond is not developed with every patient as each relationship is invested in an individual and unique way. Loss of a close relationship with a patient who has died however can result in varying

degrees of forms of grief. This grief can manifest before, during or after a patient's death.

The relationship with the loved ones compounded their feelings of sadness for the bereaved once their loved one had died. Some nurses argued that it is not professional to show emotion after the death as the nurse has a job to do; supporting the bereaved through the immediate aftermath of a death and their own display of grief would not allow this support to happen. The nurse had to stay strong to support the bereaved, sometimes to their own cost as they were unable to freely grieve for the loss of the patient with whom they had built a strong relationship. The nurse would often take a few moments away from the ward following a death to reflect and grieve privately.

The death of a patient affected nurses to varying degrees. The burden of grief or feelings of sadness were often where there was a personal relationship or connectedness with the patient and loved ones. Caring for the dying is very personal in nature and clinicians are influenced by their patients which can impact on the clinical response, even though the clinician may not be aware or acknowledge this (Katz. 2016).The setting for the study of a hospital was in a rural area which resulted in many of the nurses knowing the patients or relatives of patients they had nursed in a personal capacity. The dynamics of the relationships therefore may differ greatly to a large hospital in a city. The existence of a strong bond or friendship was not given any negative connotations by the participants, with the only the perceived weakness identified as the nurse potentially showing emotion (in front of the loved ones) after the death. Campbell (1984) discussed the notion of a skilled companion when describing the relationship between a nurse and their patient. The relationship is described as having mutuality and requires commitment but within defined limits. The nurse may feel that they had overstepped those limits through displaying open grief.

The feelings of connectedness and care extended beyond death for some nurses with the desire to carry out "last offices" or the final act of care. The process involved washing the deceased and preparing them for the mortuary. The nurse may have washed the patient many times previously and it is often during this process of delivering personal care that a

relationship is strengthened or friendship formed as trust is a key component for both the patient and the nurse. The familiar action of gathering the equipment necessary to wash the patient, ensuring the patients favourite body wash or perfume is used, making sure that the patients hair is combed in a way that they requested previously etc may evoke feelings of connectedness. The nurse carried out the almost ritual like act of delivering personal care to the patient one last time.

An opinion piece by Nyataga and Vocht (2009) describes the etymology of "offices" as deriving from Latin and *officium* which translates as duty, service or business. The final act of care for the nurse was the last service they could provide for their patients and the nurses in this study often saw it as a duty to provide the best care they could, extending the care of the dying to care of the deceased.

Nyataga and Vocht (2009) suggest there are reported benefits for those carrying out the final act of care which could include an acknowledgement of the reality of death. The person carrying out the process may achieve a fulfilment of their responsibilities through undertaking an obligation which holds tradition. This would foster a sense of completeness and allow them to convey their respect and gratitude to the deceased. This sentiment was echoed by the nurses in this study who felt the process of delivering the final act of care completed their episode of care with the patient.

The nurse described the final act of care as something that was lovingly and respectfully carried out once the loved ones have said their final goodbyes to the deceased. The NHS National Care after Death policy describes caring for a person at the end of their life, and after death, as enormously important and a privilege (Wilson & White. 2011). This sense of privilege was apparent in the content of the narrative collected from this nurses in this study. There are challenges however to providing the final act of care and a novice nurse may not be comfortable with touching a cold, deceased person for the first time as this could provoke feelings around death anxiety according to Nyatanga and Vocht (2009).

The process of care after death demonstrates respect for the deceased including cultural or spiritual beliefs but consideration to health and safety

and legal requirements should be given according to Dougherty and Lister (2004). Dignity and care should be afforded to the deceased even when issues around infection control etc are encountered. This view is echoed by Nyataga and Vocht (2009) who suggest that the final act of care should not be viewed as just another process or task to undertake. The nurse performing the final act of care should appreciate the impact on the bereaved, they are creating a peaceful image of the deceased and the bereaved know their family can take comfort, knowing their loved one is still continuing to be cared for after death.

The nurses in this study described delivering the final act of care as the last respectful thing they could do for their patient and this made the nurse feel at peace, echoing the findings of previous studies and observations (Nyataga and Vocht. 2009, Wilson & White. 2011). It was a time for personal reflection for the nurses, when they could mitigate their feelings of loss through ensuring that they were giving the best care they could, even beyond death.

Nyataga and Vocht (2009) also stress that the nurse should be aware of their own biases and perceptions around death and be mindful of their reactions and thoughts and feelings each time they deliver the final act of care. The nurse should be offered emotional support and be equipped with the skills to foster resilience to enable them to continue delivering care after death without any emotional cost to themselves. In an acute setting formal support is not routinely offered following the death of their patient but rather the nurses draw support from their team and often may reflect on the death of the patient alone.

8.4.2 Intermediate theme - Teamwork and support

The support within the team for each other was an important factor in the dynamics and philosophy of care experienced by palliative care nurses. Nurse seven originally started their career in palliative care nursing but moved to work in a community team after a period of time. The team dynamics and support within the particular community team did not fit with their sense of a job well done. In this care setting the nurses felt they had no job satisfaction and therefore returned to work in palliative care. They described the atmosphere within palliative care as like a family. The

uniqueness of the team in the level of support offered to each other held great attraction for many of the nurses.

The need for team support was described as very important particularly following a traumatic death and support from the team often affected their own ability to cope. The process of group reflection after a death was important not only for learning and passing on information and communication surrounding the death but also for the nurse to gain meaning from the event. The process of team reflection however in an acute setting is often informal and carried out during handover where time is limited.

This team behaviour was identified by Mak et al. (2013) who suggest that nurses learn from their colleagues. They describe how nurses experience a mutual learning environment whereby they learn how to incorporate dignity into their care and how to support patients and their families around acceptance of death and anticipatory grief. In their study the nurses reflected on their personal feelings and were determined to always try their best to deliver good quality care. These findings are echoed in this current study where the nurses described how they recounted the events of a death at handover to the next team. This not only served to pass on information around the event and any outstanding tasks such as the collection of the death certification but allowed the nurse to reflect within the team to make sense of the death. The process also allowed to the nurse to gain validation from their colleagues that their actions around the death were relevant and correct.

Donaghy and Devlin (2002) report that there is a value in teamwork in the palliative care setting as it helps to develop relationships, resolve conflict and enhance mutual respect and trust. They also noted that it is also important to have good support measures in place for staff. The team should be given access to peer support as well as critical incident debriefing and clinical supervision (McCloskey & Taggart. 2010).

The importance of speaking to the team about situations on the ward was emphasized and the nurses viewed their team members as their first port of call for achieving emotional support. The need to discuss events and difficult deaths was shared by all the nurses on the unit. Knowing that the team

understood the emotions surrounding a death of a patient and how deaths could affect a nurse provided support. Support from colleagues was vital to theirs and the team's wellbeing. Papadatou (2000) acknowledges that grieving for the death of a patient appears to be an individual process, however it is acknowledged and validated within a team setting. She goes on to suggest that collective sharing may give permission to professionals to grieve and present an opportunity for a sense of closure. This may be particularly important if the professional had a close bond with the patient and the patient died in the professionals absence.

Luxardo et al. (2014) concluded in their study examining palliative care staff perspectives that clinicians working in palliative care explicitly need clinical supervision and should be afforded time and space for sharing experiences.

However, there were no formal clinical supervision arrangements in place for the palliative care team in this study on the ward. The nurses could speak to senior members of the palliative care team, the chaplaincy team or self-refer to occupational health if needed. The downside of this approach meant it relied on the nurse recognising their own needs and then being proactive in seeking out help. The findings from this study suggest that nurse are reluctant to show or share their grief and may feel uncomfortable in seeking out further formal support. They may see it as a failing or not professional and therefore would be reluctant to highlight their perceived failings to their peers or line managers.

The type of preparation for the role of a palliative care nurse in an acute setting varied. The nurses in this study had not undertaken any further formal training for their role but had received "*on the job*" coaching and support, with the opportunity and funding to pursue further post graduate training if they required. The nurses who had been within the palliative care team the longest described that they sometimes did feel sad after the death of a patient, but they felt they had been "*trained up to be a professional*". This implied that it was not professional to show emotion to the patient or loved ones. They qualified this by stating that they had been trained by "*old school*" nurses and they knew how to manage distress in patients and loved ones. They were able to offer solace to them and let them know that the

nurse was there for them without becoming emotional themselves. A further description of a good nurse was one that did not crack under pressure and show emotion. Papadatou (2000) describes a traditional education approach to clinicians delivering palliative and end of life care whereby detached concern is encouraged. The clinicians were advised to control their emotions when affected by the dying and bereaved. Some nurses in this study conceded that this approach may be viewed as *"hardness"* but they felt that they, as palliative care nurses could see beyond the hard exterior and not showing emotion would be viewed as a good attribute to have in their opinion. Their early career experiences and learning from "old school" nurses shaped their approach to nursing and they saw a calm and un-emotional exterior as the preferred approach to nursing.

In support of a consistent and inclusive approach to learning and development around palliative and end of life care issues in a healthcare setting the Palliative and End of Life Care Framework document was commissioned by the Scottish Government in 2015 and developed by NHS Education for Scotland. This document provided some guidance on physical domains of care for the palliative care nurse to structure their care and learning. However no support has been offered in implementing the framework and individual boards and healthcare providers are tasked with converting the framework into practice (NHS Education for Scotland (NES). 2018; Scottish Government. 2015). The framework does not however address psychological and resilience aspects of delivering palliative and end of life care.

There was a very strong sense from the interviews carried out that it was not professional to cry or show emotion to either to the patient and their families or indeed the nurses colleagues on the unit. However analysis of the transcripts identified how often the subject arose with subtle differences in the nurses description of acceptance of displays of grief. The more experienced nurses justified their belief in hiding their feelings through being taught by "old school" nurses who were good at their job but ruled with a tight air of discipline. It was illuminating however that all the nurses were grateful for the opportunity to take part in the research and they stated they had never had the opportunity to talk openly and honestly about their

feelings surround the death of their patients previously. Some nurses described the experience as similar to a supervision session and suggested that they had felt real benefit from talking about their thoughts and feelings and would like to have the opportunity to partake in clinical supervision at a future date.

Reflection and clinical supervision as discussed elsewhere in this chapter should be part of the education programme offered to nurses at the start of their preparation for this complex role but also throughout their practice. A view echoed by Badolamenti et al. (2017) when describing the impact and consequence of poor management of emotional labour.

8.4.3 Intermediate theme - Permission to grieve

Brunelli (2005) suggests that the grieving process as a concept should be examined by all nurses. Grief is a phenomenon that all human beings will experience at one time or another. The nurse is a human being first and foremost and therefore a phenomenon attached to all human beings also applies to the nurse.

Rich (2005) describes how working with the dying and bereaved families impacts on the nurse in three ways. The death of a patient makes the nurse aware of their own losses, can contribute to their anxiety around personal fears and potential loss and add to distress around death anxiety. The nurse like the family must integrate the loss of the patient into their own personal set of circumstances and awareness. Rich (2005) concedes that the healthcare professional is vulnerable to the effect of unresolved grief and should work through their grief, the same as any individual or family member who has experienced grief. This notion posed a dilemma for some nurses participating in this study and they found difficulty in allowing themselves to experience grief for their patients.

The consensus that emerged from many of the experienced nurses was that it is not professional to show grief or emotion. Conversely this was contradicted by some nurses openly showing grief to the bereaved loved ones and colleagues. Papadatou (2000) confirms that some clinicians may grieve or experience loss for their patients and loved ones and their own unmet goals. This theme also links with a previous theme of you are a

person not just a nurse. In their expression of their emotion the nurse is showing their humane qualities and their emotional investment in the dying and the bereaved.

All of the nurses interviewed discussed hiding their emotions whilst on the ward and waiting until they got home to openly cry. They acknowledged that the nurse's grief is not the same level as the loved ones and they could not engage emotionally to the same level as the families, but they did feel some level of grief. Papadatou (2000) developed a model of grief for professionals which describes the oscillation between experiencing grief and avoiding grief – similar to the description of behaviours of the nurses from this study. According to Papadatou (2000) a problem arises when the clinician becomes fixed in either of the situations. This built upon a bereavement task model aimed at nurses earlier proposed by Saunders and Valente (1994) in which they suggested that nurses could successfully manage their grief through undertaking the tasks of finding meaning, maintaining and restoring integrity, realigning relationships and managing affect.

The nurses in the study did try to work through their grief or sadness at the loss of their patients but within a busy acute ward it is not uncommon to experience three or four deaths a week. The nurse must simultaneously manage various stages of preparing for the death, experiencing the loss, making meaning of the death and moving on to care for the remaining patients. Several different stages of being could potentially be experienced at one time and this could prove difficult for the nurse to manage. Nunes et al (2018) concede that the transference of death to institutional environments does place heavy demands on the nurses delivering care. The repeated experience of death can be highly challenging and evidence shows that they are affected by continual exposure to others loss. Papadatou (2000) cautions against using traditional theories of grief which refer to the loss of loved ones who's internal and external world are affected by the loss. These models do not apply to the health professional who face pain, suffering and death throughout their profession on a daily basis as there are differences in relationships, connectedness, dynamics and significant bonds between a patient and their loved one.

One nurse explained how they did not think it was their grief to deal with and by presuming they could experience grief for the deceased patient would be disrespectful to the loved ones. They felt they did not have permission to grieve. They qualified this by stating that this was the correct approach to take as becoming emotional after every death would not be sustainable and they could not carry on with their work in palliative care. In their view the ability to switch off their emotions contributed to them being a good palliative care nurse which allowed them to see the wider picture and emotion would not be beneficial to delivering care to the bereaved loved ones or others. These thoughts were echoed by Strada (2013) who acknowledges that clinicians facing several opportunities to face grief may suppress their emotions as an adaptive modality which becomes the main coping mechanism. Brunelli (2005) also supports this view and describes maladaptive grieving as a potential forerunner to emotional distancing, depression and burn out.

Tinnion (2019) in her opinion piece suggests that some stigma remains in nursing around feeling emotion following a patient's death but that things are starting to change now. She describes grieving for patients who have died. A relationship over a period of time had developed and Tinnion reflected on the emotions experienced after the patient's death and understood that it was a normal and natural response because she cared about the patient with this care and concern contributed to delivering good quality care. Tinnion delivers care in a community setting and therefore has much more opportunity to develop lasting and therapeutic relationships with her patients and even goes so far as to say that if she did not feel some form of grief could she honestly say "*that she had done her job well* " (Tinnion 2019).This approach however may not be as easily transferred to an acute hospital setting. The focus in acute settings is often task orientated. There is little time afforded to developing relationships and reflection after the death of a patient is not factored into a busy acute environment..

A lot of importance was place on being able to deal with one's own emotions by those interviewed and those nurses who could not, were regarded as unsuitable for a career in palliative nursing by one nurse. They described their concern if a colleague showed signs of distress on a regular basis and

if so they would encourage them to seek support by somebody trained in clinical supervision and would question their suitability for the role. This may appear to be unsupportive to their colleagues who may be struggling with professional grief and could impact on the team dynamics.

Another nurse began to describe how they did not think it was professional to openly show emotion although they sometimes succumb to emotion and cry. They would then take a deep breath and continue with their work, usually they would go home at night and reflect on the death. As an example of this the nurse then described one patient who they had a particularly close relationship with and the relationship with the patient's daughters continued after the patient's death. The daughters collected rose petals from the patient's garden for the nurses wedding and the deceased patient had left a signed card for the nurse. The nurse started to cry as they recalled the act of kindness from the patient and her daughters and said she felt that a small part of the patient was at her wedding. The nurse apologised for crying and said she was being "stupid". The nurse also stated that she did not think she would "be like this". This was an example of the nurse believing that they were not being professional and were unable to manage their emotions.

Papadatou (2000) describes how some professionals do not grieve for patients immediately after their death and often postpone or repress their grief. This grief can then resurface when they least expect it. This particular nurse did not state that they suppressed their grief following the patient's death but was surprised at the depth of feelings that emerged following the recounting the story of the patients death and the connection they had with the patients family thereafter. A further layer of understanding comes from Stayt (2010), in her opinion piece suggests that some deaths are more significant to nurses than others. If the nurse develops empathy with the patient and their family then a meaningful engagement or personal bond is formed. Whilst this engagement is described as fulfilling, the danger is that the more meaningful the relationship is the greater potential for experiencing grief when the patient dies.

Personal reflection was deemed to be very important to most of the nurses interviewed and they used it as a way of remembering and making meaning of the death of their patients. They also found it useful for other areas of work or study and even used it in their personal life outside and not connected to work. Cheng et al (2013) concluded from their study that a strong team climate could provide effective strategies to mitigate the negative effect of emotional labour and burnout. They assert that hospital managers should work towards building strong teams with supportive climates to help nurses manage the emotional demands expected of them. Some of the nurses in this study did not appear to display a supportive climate. Doka (2014) describes the change in perspective from earlier schools of thought that healthcare professionals should not show emotion in front of their patients and loved ones, he acknowledges that in practice it would be very difficult to hide feelings of grief or loss.

Cheng et al. (2013) conducted qualitative research around the role of team climate in the management of emotional labour in Australia. The potential for emotional dissonance was discussed. Emotional dissonance is described as a difference between the persons internal feelings and the emotion they are displaying. This approach and emotional dissonance may be an attempt to align to the display rules of the organisation or team. Through striving to meet the often unspoken rules may result in emotional exhaustion and ultimately burnout for nurses.

If the participants of this study were encouraged to provide a supportive climate to discuss each death, then their colleagues may be able to reflect more openly within their own team and so mitigate the potential for grief and loss.

There is some evidence of professional grief in many specialities not just palliative care but there is a lack of representation for a full range of disciplines in the literature. Studies in the past have tended to concentrate on paediatric or oncology clinicians. The methods for addressing the grief experienced by clinicians has not been defined in recent literature and there is a need for a wide-ranging assessment and comprehensive description of clinicians grief in general as well as the need to address clinician grief

across a large range of disciplines (Carton & Hupcey. 2014). Papadatou (2000) suggests that clinicians experience vicarious grief for the family – through identification with them and proposed a model of the health professionals grieving process which conceptualises their reactions to multiple deaths of their patients. The health professionals fluctuate between focusing on the loss and repressing or avoiding grief. Saunders and Valente (1994) suggested that nurses could successfully manage their grief through undertaking the tasks of finding meaning, maintaining and restoring integrity, realigning relationships and managing affect. Brunelli (2005) also recognises that nurses need to work through their grieving process and reach a healthy resolution with a patient's death in order to maintain physical, mental and spiritual health.

8.4.4 Intermediate theme - Moving on

A task based approach to grief theory favoured by Worden (1991) is based on moving from a passive stage of grief to active stages of grief. Task one of acceptance of the reality of loss. Task two is working through the pain of grief and accepting that it is a necessary process. Three is adjusting to a new environment and readjustment may occur over an extended period of time. Task four is finding an enduring connection with the deceased while moving forward with life. Memories of the deceased must be maintained but the bereaved must be able to accept the loss and move on with their life.

Six of the seven nurses discussed letting go and moving on to the next patient as a way of managing their emotions and grief. One nurse described the feeling as sadness after a death, suggesting that the term grief was too strong a description. They conceded that they were human and had feelings, but they were very wary of allowing themselves to get too deeply involved as they would then enter into a grieving process. They would not be able to move on and look after the remaining patients. They try to put a halt to their grief. Another nurse described the feeling as grief which was very short lived unlike the family's grief which would continue for weeks and months. A short burst of sometimes severe grief is experienced which may last for a day or two. The nurse then compartmentalises the grief to enable them to continue caring for the remaining patients who may also be facing death

soon. Papadatou (2000) concedes that a wide variety of grief reactions are experienced by health professionals following a death but for some reactions of sorrow, anger, guilt or despair can be intense. These reactions however may only last a few hours or days but can occasionally can continue for a few months.

Several of the nurses described having to engage with other patients and family members and provide the best care they could. In order to do this, they needed to "clean the slate" and "put on a new head for a new day". Carer grief is similar to other types of loss however Papadatou (2000) highlights the recurring exposure to grief which necessitates the health care provider to oscillate between containing their grief and experiencing their grief in order to allow them to continue caring for the dying and bereaved. The extracts above appeared to be describing the nurses containing their grief, however the attitude to grief can and does vary from nurse to nurse and not all nurses undergo a negative experience following a patient's death or a period of grief for that patient. Sinclair (2011) suggests that having a repeated exposure to death and dying may indicate a mostly negative impact but the findings from his study showed the opposite. Affirming life lessons were gleaned from the clinicians care of the dying and an opportunity to integrate end of life wisdom into their lives which had been discovered whilst sitting at the bedside of those approaching death. This approach may in fact bolster the nurses to continue providing good quality care to other patients approaching death. The nurse is in position to support patients and enable the period of care to be a meaningful episode of the patients life. The nurses participating in this study echoed some of Sinclair's findings. The nurses wanted to support the patient and their loved ones and provide a safe space. They understood the importance of being with and alongside and often described caring for the dying as a privilege.

A final observation was made by nurse four that when they arrive on shift they check the patient name board on the ward to see the list of patients. If they identify that a patient has died since their last shift they will comment and acknowledge the death but then move onto their tasks for that day and appear to forget about the patient who has died. They confirmed that they do not let it sink in and stop it reaching so deeply within them as then it

becomes more real and the consequences are they may experience grief. They are aware that to somebody outside the palliative care area witnessing their attitude to the information that a patient has died, their actions may appear unfeeling, but they reiterated that this mediation of their response is necessary to protect their own emotions. This apparent indifference to the patient's death was not a reflection of the nurses lack of care and concern for the patients but an acknowledgement that they had performed their role as a team to deliver care to the best of their ability. If the patient had experienced a difficult death or did not have family in attendance then more time was spent reflecting as a team and support offered to colleagues from the incoming team. It was important for the team to share that the patient did not die alone if family were not in attendance, a significant point which holds great importance for the nurses on the unit. It is symbolic of the care and respect afforded to the dying patient, the nurse supporting the patient until the very end. It may also be a genuine response of acceptance and moving on as according to Sinclair (2011) exposure to dying patients can be a positive experience resulting in greater meaning in life, self discovery and belief in the continuity of life.

8.4.5 Conclusion of superordinate theme 3. – separating the personal and the professional self

The nurse often finds difficulty in separating the personal and professional self as their own identity is rooted in their profession. Relationships were given high importance and the description of skilled companion describes the mutuality and commitment encountered by the nurse delivering end of life care.

Carrying out last offices was perceived as the final act of care and allowed the nurse to say their goodbyes and complete their episode of care.

The level of experience and preparation for the role the nurse had undertaken appeared to influence their ability to manage their emotions. Support from their colleagues was invaluable in allowing them to collectively share their grief and make meaning of multiple deaths.

There was a perception however that permission to grieve was not freely given by "*old school*" nurses and they therefore often tried to show a professional side. Additionally they would not share their feelings with the team if they thought this would be viewed negatively and an inability to cope. The transfer of death to an institutional environment away from a hospice setting could contribute to these negative feelings.

There were no formal structures in place for clinical supervision or reflection to mitigate their feelings of loss. There is evidence that good clinical supervision is imperative to support nurses following the death of patients and in particular when multiple deaths are experienced. This support is widely available in hospice settings but severely lacking in acute settings and research has not been conducted to date to illuminate this gap in unmet needs.

The nurses dealt with death by acknowledging the death then letting go in order to move on and be able to continue delivering care to the remainder of the patients and loved ones on the ward. This became difficult however if they had experienced a difficult death with negative connotations.

8.5 Discussing the superordinate theme 4. - Death anxiety and transference

Free coding	Intermediate themes	Superordinate theme
Young age difficult – relate to self.	Too young to die	4. Death anxiety and transference
Death anxiety linked to young age.		
Young age affects your emotions		
Difficult if young children involved		
Relate older patients to their own parents.	Standing in the shoes of the bereaved	
Putting themselves in the parents shoes – wrong thing to do.		
Personal experience of death and dying and wanting to improve care.		
Connection with patient or family		
Your child dying is every mothers biggest fear.		
Can be difficult to understand when patient knows they are going to die and accepting of it.	It could be me -I don't want to die	
Anxiety about not having children before they die.		
Try not to put myself in their shoes.		
Everyone is afraid of death		
A good death being surrounded by loved ones and dying alone is sad.		
Question if you could stay in PC long term.	Resilience	
Break needed so not too emotionally drained.		
The more experience of dying patients the better you become at dealing with it		
Need to normalise death		
Fear that to them death is normal.		
They don't worry about death		
Must be grief somewhere inside.		
Do question what its all about		
There can be positive aspects too.		

Table 10 Table of themes for " Death anxiety and transference"

As the nurse faced difficulty in separating the personal and professional beliefs and values the duality of their role sometimes caused difficulty in managing their emotions. As the participants previously expressed they are people with their own thoughts and feelings, working in an environment with multiple deaths which provokes feelings of loss or grief, not only for the patients and loved ones but also for the clinicians caring for them. This is a view shared by Papadatou (2000) when describing paediatric oncology health professionals view of death and dying when caring for children approaching death.

The phenomenon of transference emerged throughout the theme of death anxiety and can be described as; feelings that are brought to a clinical relationship that have been provoked by the patients state of being or behaviour, within a therapeutic context (Luban & Katz. 2016). The emotional responses and transference experienced by nurses when delivering end of life care should be recognised and used as a base on which their humanity stands. The acknowledgement that their humanity is the essence of the care they give should also serve to make them cognisant of the necessary limits which are inherent in providing end of life care according to Doka (2016)

Anxiety around death and transference was displayed throughout the interviews conducted. The nurses were asked directly about their thoughts and emotions leading up to a death, at the moment of death and following a death. Four intermediate themes emerged. The first theme of "too young to die" focused on the age of the patient at end of life and the feelings that were evoked looking after them as they approached death. They then went on to reflect on the emotions and pain caused to the bereaved and associated their own feelings of loss with them which emerged as the second theme of "standing in the shoes of the bereaved" . The third theme of "it could be me" arose as often the nurses associated with the dying patient directly and discussed openly their own fear of death. The final theme of resilience was an important point of discussion in all the interviews, allowing the nurse to heal and move on.

8.5.1 Intermediate theme - Too young to die

The fear of dying at a young age was evident in most of the interviews, but also the difficulty in managing feelings when caring for a younger patient who was approaching death was also identified. If the patient was elderly the sense of acceptance was common amongst the nurses. The assumption that the patient had led a long and full life was acknowledged and the end to that life was normal and expected. These were assumptions by the nurse as often they knew little of the life the patient had led. However, they recognised the natural order of things were being allowed to play out. Their role was to ease the passage of death and be there to support the dying and bereaved along the journey to the inevitable end. Death could be thought as a stage in life's journey with several aspects such as medical, psychological and existential components all contributing (Kellehear. 2009). This view may help to counter balance the health professional's negative association with the death of their patient and was demonstrated in the findings in this study.

In contrast when a patient was young this usually caused deep concern to the nurse and prompted them to reflect on the patients age. The ward was an adult unit, so the young age did not relate to children under eighteen and young was perceived as anybody who was not elderly in the accepted sense.

The literature search conducted did not present any studies conducted or references pertaining to this particular aspect. There is some evidence around distress clinicians face when dealing with the death of children according to Papadatou (2000) but this does not relate directly to this study but similarities can be drawn.

The nurses in this study felt it was unfair that somebody so young should die without living a full life. They felt that the patient had unfinished business and the death would impact greatly on the bereaved as the death was unfair. Papadatou (2000) discussed her experience derived from her extensive past experience as a clinical psychologist working in a paediatric hospital in Athens and some similarities may be drawn but the care of dying children is distinctly different to caring for dying adults. Papadatou (2000) however does suggest that losses which are related to the nurse's personal system of

assumptions and beliefs with regard to life can trigger intense feelings of meaninglessness when order and predictability are not achieved. If the nurse cannot exert control and feel the world is not equitable and just, they may experience poignant grief reactions, especially around those deaths which include children or young adults.

The nurses interviewed all had stories around the death of a younger patient and one particular patient who was very young was discussed by four of the nurses independently. The collective emotional burden on the team was very apparent. From a positive perspective, the team understood each other's grief however and were able to offer support to each other.

If the dying patient also had young children, then the distress for most of the nurses was increased. The concern for the remaining family and wellbeing of the children was an important factor and influenced the care plan and delivery of care. Bereavement care is an intrinsic part of palliative care nursing but can be very difficult when the nurse is trying to manage their own emotions and offer support to the patient and possibly the patients parents and children. Nurse seven describes experiencing a surge of emotion when a patient dies but usually they are able to control it. However when a young patient dies this was definitely more difficult to deal with. This description of their grief related to the loss of their personal system of assumptions and beliefs as described by Papadatou (2000).

The death of patients who are young or have young family cause the greatest upset for the individual nurses providing the care but also to the team as a whole. The team would be aware that the individual nurse may need support and be ready to offer solace and comfort if they were required.

Brunelli (2005) in her concept analysis of the grieving process for nurses describes the death of a child for whom she was the primary nurse. She describes the difficult journey the patient endured whilst hoping for a cure. The patient died after deteriorating following treatment and the patient's death was mourned by all who cared for her. Brunelli (2005) goes on to suggest that the grieving process is a concept that nurses should examine because the phenomena of grief is something that every human being will experience. She asks" *who will assist the nurse who spends time dealing*

with the suffering ?". Brunelli's (2005) description is of nurses working in a paediatric oncology unit and she proposes that all nurses will experience the death of a patient at some time in their career however, for those nurses working in areas with patients who have a poor prognosis the loss will be repetitive. This will put a physical, mental and spiritual burden on the nurse, not only as nurses but also as human beings. She suggests that nurses need to take care of themselves and each other in order to survive and thrive in a health care environment.

8.5.2 Intermediate theme - Standing in the shoes of the bereaved

Four of the nurses in the study discussed the tendency to relate to the dying patient through their own family members or loved ones. One of the nurses drew parallels between the patients and their own parents. A further nurse described how they associated themselves with a family member of the dying patient and two nurses associated with the patient and their relationship with their children. Strada (2013) describes how palliative care clinicians can develop empathic and close relationships with patients and may remind them of personal experiences they had with loved ones. Worden (1991) also reminds us that working with the bereaved can sometimes remind the health professional of their own loss. Osband (2006) agrees that the therapist cannot disown their own existence and life experience when working with the bereaved, however it does impact on their relationship with them positively or negatively. Katz (2016) describes transference as inevitable when clinicians are caring for the dying but there is a danger that it could become dominant if common characteristics are shared between clinician and patient or family members. To address this phenomena then clinicians should be aware of their feelings and take steps to ensure they do not result in a destructive sense of being.

Nurse one discussed relating the death of the patient to their own parents. This association was based on both being of similar age and backgrounds. The nurse started to imagine how it would feel like for her if her parents were dying and these evoked strong feelings of sadness for herself, grief for her

patient and concern and empathy for their loved ones. Lopez (2006) describes the difficulty that helping professionals in end of life care have in separating their worlds from their patients' worlds. The findings in this study support this assertion. Lopez (2006) goes on to suggest that it can sometimes be overlooked but should be noted and clinical supervision offered to help separate the needs and experiences of the care giver from the patient. Nurse five described how the death of a close family member impacted on them and influenced their career choice to become a palliative care nurse. In contrast to the scenario discussed above this nurse had experienced the death of a close family member and wanted to help mitigate the feelings of grief and loss experienced by the patients loved ones after their death. The nurse felt that through being present, delivering good quality end of life care and offering help and support to the bereaved that they could make a difference. This would contrast with their own experience of losing a loved one where they felt alone and unsupported. They admitted the memory of the experience was still very "*raw*" for them some years later. Dearmond (2013) suggests that hospice workers unconsciously seek out encounters with the dying and deceased as a means to prepare for their own death. Alternatively they may also have a desire to "heal" in the psychological and spiritual sense. Nurse five displayed a desire to "heal" others who were experiencing loss, just as they had done some years earlier. Whilst Dearmond describes clinicians working in a hospice environment, the wounded healer phenomenon of a mutual exchange of "healing" could be applied to the actions described by this nurse in an acute setting.

Nurse seven described the fear of losing their own children and compared the age of the patient to their own adult child. The nurse went on to describe their intention to empathise with the patient's mother but described the difficulties this presented. The nurse found it very difficult to imagine what the bereaved mother was experiencing and undergoing. They speculated that losing a child would be every mother's greatest fear. If the clinician is afraid of experiencing fear and pain and does not acknowledge this within themselves they may risk denying theses feelings in their patients which could lead to further distress for the patient according to Arbore et al. (2016).

The nurse in this example did acknowledge their own fear and distress but still found it difficult to explore these feelings and support the dying and bereaved. Arbore et al. (2016) suggest that by admitting to feelings of transference then an opportunity is given to increase the clinicians compassion in the face of suffering. Through investment in the self and recognition of feelings, the clinician can sustain the ability to truly "be" with the patient or bereaved rather than "do" to the patient or bereaved.

The nurse then went on to describe another situation where a mother had lost her daughter and they were trying to support the bereaved mother immediately following the death. They felt it was their role to support the bereaved mother but found it difficult as they were imagining themselves in the shoes of the bereaved.

This connection with the patient or connection with the loved one prompted an association with the situation which the nurse related to their own personal circumstances. They imagined how it would feel to be the patient or the bereaved and the impact that would have on their emotions. This phenomena could be described as death anxiety which Neimeyer (1994) asserts is the anticipation of one's own death or the fear of death and dying of oneself or those important to them.

Nurse two also described how after a period of reflection following the death of a young patient they identified that they had experienced transference with the parent of the deceased. The situation was a young adult who was dying, and the nurse was comforting the patient's parents. The nurse imagined her own grief and reaction if it was her child dying. The nurse went on to rebuke themselves for allowing that thought as they described "putting themselves in their shoes" and making the situation about the nurse's feelings and not the bereaved parents feelings. They stated that the nurse should not do that because the situation involved the deceased and their parents not the nurse. The nurse did concede however that sometimes the nurse did that as they could relate to the patient or bereaved. Worden (2009) however suggests that healthcare professionals should practice active grieving. They should allow themselves to experience the sadness and grief after a patient dies. Osband (2006) describes an opportunity for transference

to create a mutual healing where the shared experience can create a connection.

8.5.2 Intermediate theme - It could be me - I don't want to die

Caring for patients as they approach the end of their life may serve as a constant reminder to nurses of how fragile their own lives are according to Nyatanga (2019). This may increase their worries around their own death and result in an increase in death anxiety which builds on their existential anxiety. The findings from this study echo these assertions and are demonstrated in the following account described here.

Often the nurses in this study would relate directly to the patient or identify with their values. If the patient behaved in a particular way that did not match the nurse's norms or world views then this could also present problems through prompting the nurse to ask questions of themselves and their own views. Nurse one demonstrated this opposing world view when they described a scenario where a patient was approaching death and was accepting of the situation, had made their peace and were ready to die. The patient said they hoped they would still not be there when the nurse returned from annual leave in a fortnights time. The nurse found this very difficult to accept, that the patient was resigned and almost willing to die. The nurse questioned how the patient could be so accepting of death but conjectured that they, the nurse felt unable to accept death as they were still young. The nurse reflected that the patient was older and had led a full life and this may have influenced the patients thoughts and acceptance of their death. The nurse then proceeded to describe their fear of death. They conceded that it was irrational as they themselves were young but facing death frequently and sometimes on a daily basis did make them consider their own mortality. Peters et al. (2013) conducted a literature review on how death anxiety impacts nurses caring for patients at end of life. They concluded that some nurses use avoidance strategies to avoid anticipated threat to wellbeing. They found from one review that some nurses may request that they are not required to work with and care for a dying child as this would be a very stressful situation to cope with. The example of the nurse in this study fits with the technique described by Peters et al. (2013) used to avoid stressful

situations, the flight response. Peters et al. (2013) argue that the flight response allows nurses to distance themselves from stressful situations but this may ultimately result negatively on their clinical skills performance. The participants in this study recognised the need to fully engage with the patient and the bereaved family in order to deliver care that was required and ensure that their clinical skills were delivered to the best of their ability but often found it difficult to do so.

When describing grief counsellors managing their own irrational fears around death, Worden (1991) discusses existential anxiety and the counsellors personal death awareness. He states that everyone is anxious to one degree or another but being in touch with the inevitability of death can impact on the health professional in a negative way. The nurse described how the age of the patient impacted negatively on their emotions. They stated that if the patient was young and had not had chance to start a family the nurse saw this as adding to the sadness. The nurse associated with the age group of the patient and the life stage they were at. Older patients who were perceived to have lived a full and happy life did not provoke the same negative emotions.

The fear of dying alone emerged in some of the interviews and a good death was equated to being surrounded by family and friends and a bad death to dying alone. Some nurses assumed that the patient would want and need loved ones around them at the time of their death and this would be easier for the patient but also for the nurse as they would know they were not on their own. The fear of dying alone was a prominent topic which emerged several times throughout one interview in particular. The nurse asserted that other nurses in general would grieve more for a young person who died alone without family or friends than an elderly person who again had a full life and was surrounded by family and friends on the time of their death.

Nurse four explained that everybody is afraid of death but that it is a normal process and part of life which is inevitable. They saw their role as trying to normalise the situation. In his ethnographic enquiry, Sinclair (2011) describes how frequent exposure to the dying and deceased provides an authoritative perspective for the nurse. The nurses in his study did describe the ugliness

of death but tempered this with a description of the end of life stage as meaningful which helped to diminish the fear and anxiety surrounding death. This acknowledgement allowed the nurses to normalise death and enhance their meaning of life. The nurses in this study demonstrated the same perspectives held by the nurses in Sinclair's study and strove to support the dying and bereaved. They felt responsible for being the calming influence as the patient approaches death and discussed respecting each other and offering support at that time. They felt that if they could be strong and show that there could be some control over the process then this could contribute to a good experience for the dying and bereaved and possibly take away some of their fear.

Peters et al. (2013) following their literature review of death anxiety impacting nurses caring for patients at end of life concluded that nurses should have insight into their personal beliefs about death and dying in order to have objectivity in caring for patients and the bereaved. They went on to assert that nurses with a positive attitude towards death were more likely to have a positive attitude towards delivering end of life care. Luxardo et al (2014) however warns against the assumption that palliative care nurses have an open approach to death and dying. Most nurses do perceive that dying is natural and expected and that they can provide technical and emotional support as required. There are some patients however that touch the nurses emotionally as they see something in the patients which remind them of themselves. Great strain can be exerted on nurses delivering care to the dying and deceased in acute settings according to Mak et al. (2013). Avoidance techniques were reported by the nurses in their study with the nurse specifically avoiding the patients and their families in order to allow their emotional responses to be disconnected. Generally the nurses in this study however did display insight into death and dying and the implications on their care delivery and support for the patient and their families.

8.5.3 Intermediate theme - Resilience

The theme of resilience emerged in relation to death anxiety and transference. Every nurse interviewed discussed the concept of resilience

without necessarily being explicit in the description of resilience in relation to dealing with death on a regular basis. Doka (2014) suggested that effective carers possess resilience as they have learned how to cope and can easily adapt to difficult and sometimes stressful situations. They are able to bounce back and learn from past events.

The nurses in this study described the need to carry out their role regardless of the number of deaths experienced. It was expected and required to continue delivering good quality care to the remainder of the patients on the ward. They saw their role as one of support and creating a calm environment where the patients and loved ones could trust the nurse to take control of the situation and take away some of the fear. If the nurse felt calm and in control they could manage their own anxieties and stress levels.

The longevity of a career in palliative and end of life care was discussed by three nurses. Some nurses questioned if they could sustain a career where they experienced death on a daily basis for a long period of time. The desire to return to a role where cure not care was the focus was suggested as an option after several years in palliative and end of life care. Nurse two commented that it was difficult emotionally and physically but the rewards of the job outweighed the physical and emotional impact on them and this made them not consider or dwell on the damage that may be being done. This discussion however prompted the nurse to question the sustainability of their chosen career. Taking a break from working in the palliative ward was seen as a welcome relief and necessary to allow the nurse to "*re-charge their batteries*". This would be especially beneficial after an intense spell where many deaths were encountered over a few days which resulted in a lot of emotional strain on the team. The depth of experience gained however mitigated the emotional drain, with the perception that the more deaths the nurse had dealt with, then the easier it was for them to manage their own thoughts and emotions and normalise death. Sinclair (2011) suggest that clinicians frequent exposure to death which resulted in them acknowledging the deaths and integrating them into their lives resulted in a normalisation of death and could enhance meaning in life.

In contrast to this view, professional burnout however is a phenomena which describes continued exposure to stressful situations (Freudenberger 1974). Death anxiety resulting from continued exposure to dying episodes results in a reduced ability to cope with stress. This affects resilience and leads to burnout syndrome which in turn leads to an inability to cope, ill health and high absenteeism according to Nyatanga (2019).

Brunelli (2005) suggests that emotional distancing and burnout could result from maladaptive grieving on the part of the nurse. From the discussion with the nurses it is clear that whilst the nurse purports that they can manage their own emotions they acknowledge that there is sometimes a cost to continued exposure to death, dying and stressful situations.

The concept of emotional distancing was considered by nurse seven who questioned if seeing death as normal was acceptable. Death had become part of their life and did not present any undue stress if the death was managed well and the nurse felt in control. The nurse explored the concept that because they experienced so many deaths that they may have become un-feeling towards it. They suggested however that feeling like that was not normal. If they did not work in the field of palliative and end of life care they may not have the same attitude to death and dying. They said that they did think about death but did not worry about it, however later in the interview when returning to the question of transference they did confirm that most nurses worry about death and dying or terminal illness but again reiterated that that was also normal. They concluded by saying that death to them was normal and they acknowledge the death of a patient but did not dwell upon it. They did not let the grief or sadness sink in and only allowed it to go so far. This way they could continue with delivering care to the rest of the patients on the ward. Melvin (2012) concluded that nurses delivering palliative and end of life care do experience emotional and physical health consequences over time but the risks can be mitigated by setting boundaries and employing other healthy coping strategies. Early identification of issues is paramount in being able to offer help and support to nurses undergoing difficulties managing their thoughts and emotions around death and dying and delivering end of life care.

One nurse asserted that everybody, including themselves is afraid of dying. They suggested that they try to help the patient and family members through the grief process, including anticipatory grief but they would never put themselves "*in their shoes*" as they felt it was not the nurses grief to experience. The nurse understood the phenomena of professional grief as something which should be avoided.

Doka (1989) suggests that the term given to this understanding is disenfranchised grief i.e. grief experienced by a person who does not fit with accepted social norms of those who are expected to grieve. Carton and Hupcey (2014) assert that healthcare providers are victims of the disenfranchised grief that Doka describes and they advise that there has been further research which corroborates this assertion. They go on to suggest that if the health care professional does not acknowledge the forbidden grief then unhealthy coping patterns may develop. The nurse from this study may go on to develop unhealthy coping patterns but may also be managing their own emotions through setting boundaries and developing coping strategies which fit with their world view. Through acknowledging the normalcy of experiencing negative emotions, Doka (2019) suggests that an opportunity arises for organisations and individuals to recognise issues such as moral distress or disenfranchised grief. When the death of some patients affect the nurse due to a close connection or bond then support can be offered to allow the nurse to discuss their emotions, reactions and concerns.

This process could be described as emotional labour. Emotional labour is a complex subject which not only describes the management of expression and display of emotions but also concerns the interpersonal relationships that emerge as part of the caring process (Badolamenti et al. 2017). Bolton (2000) identified that understanding and managing emotions is an important area within nursing practice. Emotional labour entails the nurse working with their emotions to ensure they appear professional. Bolton (2000) does concede however that emotional engagement is often altruistic in nature. Bolton's (2000) study identified that nurses offered additional acts of thought when delivering care, although not seen as part of their job description, they believed that delivering care in this way was intrinsic in their identity as a nurse (Bolton. 2000). He describes the act of offering additional emotion as

a gift which is freely given, ascertaining however that the nurse cannot truly share in the grief of their patients due to the perceived need to remain professional in their demeanour.

Worden (1991) suggests that health care professionals working in palliative and end of life care should know their own limitations. He suggests that there is a limit to the number of dying patients a counsellor can work with as an inevitable attachment will occur with each patient. As each patient dies then grief will be experienced. If the counsellor has a large number of patients they are caring for, then the potential to experience a large number of episodes of grief exist when the patient dies. This many episodes of grief within a relatively short period of time may become overwhelming for the counsellor. Whilst Worden is describing the relationship between patient and grief counsellor similarities could be drawn to other health professionals working in palliative and end of life care. In contrast, Sinclair (2011) found that repeated exposure to death and dying in a palliative care setting did not have a negative impact on the health care providers lives. The participants in his study discussed the life affirming lessons that were incorporated into their own lives as a consequence of delivering care at end of life. He argues that whilst approaching death is one of the most challenging phases of life it is also one of the most meaningful and this offers hope to those facing their own mortality. Dobrina et al (2014) conclude that nurses themselves could also experience existential growth when caring for the dying which would give both personal and professional satisfaction. In contrast Nyatanga (2019) concedes that whilst it is a privilege to part of the intimate dying experience of a patient when delivering care, warns that this can be a double edged sword, as exposure to death anxiety can lead to stress and burnout.

Many of the nurses mentioned reflection in relation to many different points discussed throughout the interviews but all concluded that reflection was a very powerful tool to manage their emotions, make sense of events and improve their resilience. It was described as empowering by one nurse who used it affirm the role as a compassionate nurse and supporting presence for the dying, stating that reflection helped counteract the negativity and sadness by bringing out the positive as well.

8.5.4 Conclusion of superordinate theme 4. – death anxiety and transference

Death anxiety and transference were often a consequence of the nurses questioning of their own beliefs and fears surrounding death. Feelings of loss and grief can contribute to their personal system of assumptions and beliefs and trigger intense feelings, particularly around younger patients or those leaving a family after their death.

Transference was recognised by many of the nurses and they often felt an association with the bereaved loved ones which also provoked feelings of empathy and sadness.

Death anxiety sometimes impacted on their objectivity when caring for the dying. Their own fear of dying or losing a loved one became more acute if they had a relationship and connection with the dying patient and loved ones. They did however note the irrationality of comparing themselves or family members to the situation they were dealing with and tried not to put themselves "*in their shoes*".

The nurses also expressed their pride in their own resilience and described how they did become upset on some occasions when patient died but often tried to hide their grief and saw this as a form of resilience and being able to cope. This may have been counterproductive as most of the nurses became upset and emotional during the interviews held and apologised for showing their grief. They all however agreed that the process of participating in the study had been cathartic as they had never had the opportunity to discuss their experiences of patient death in such depth previously.

8.6   Making meaning and revealing the gestalt

Making meaning can be described as a social act where the person interprets the actions or events and understands and accepts the situation within a symbolic framework (Nadeau. 2001). Further to this Papadatou (2000) describes team meaning making as a social act whereby members within a team interpret the death of a patient within the context of their team

or unit. They then go on to represent the situation to themselves and each other within this framework. The preceding discussion illuminated a process of meaning making for the individual but also within a team structure. Making meaning includes many layers and complexities and through the process of IPA analysis of the experiences of the nurses in this study a phenomena was revealed. The phenomena could be described as a gestalt which is a structure or experience that when considered as a whole, has qualities that are more than the total of all its parts. It became apparent throughout the analysis that each theme impacted and informed the next. Taken as a standalone theme, interpretation can be developed and presented, however the rich interdependence of each theme pointed to a much more powerful presentation of findings and therefore discussion when viewed as a whole.

Upon completion of analysis for all seven of the interviews, discussion of each theme was developed, in this way the framework or gestalt was further developed.

The theme of the importance of being drew on the deeply held belief that the most important gift a nurse can give to the dying is their authentic self and truly be with the patient or bereaved. The nurses felt that it was a duty they freely undertook with an altruistic approach. This approach often caused some confusion and internal angst separating the personal and professional self can present difficulties as the two are entwined and together engender the self. Whilst the nurses strive to deliver good quality care and support the patient and their loved ones through the process of dying and bereavement, the nurse may encounter transference and ultimately death anxiety which may lead to burnout and emotional drain. Support therefore is imperative to mitigate the feelings of loss counter the effects of burnout.

This chapter aimed to understand and make meaning of the component parts or themes. The sum of the component parts of this analysis and discussion form the unified whole. The gestalt and final conclusions are presented in Chapter nine.

Chapter 9
Presenting the gestalt and conclusion

9.1   Introduction

This chapter explores the themes and discussion presented in Chapter eight and draws them together to illuminate the connections therein. The themes and discussion are presented to describe the phenomenon of palliative nurses grief within the context of care of the dying and deceased in a palliative care ward within an acute hospital. The literature discussed in chapter two highlighted the relatively new understanding around the discipline of palliative care. No literature was found to highlight a theoretical understanding of palliative care nurses grief when delivering care in acute settings. To this end literature around characteristics of the palliative care nurse and theories of professional grief were examined in order to draw parallels between available knowledge base and the findings presented in Chapter seven. The four themes which emerged were the importance of being, the altruistic self, separating the personal and the professional and finally death anxiety and transference. These are intrinsically linked and one theme informs the other. The sum of the four themes is greater than the simple analysis of each theme as a distinct phenomena.

Presenting the gestalt will expand the findings and discussion chapter further, referring back to previous sections which explain the role of the researcher within IPA. It will also describe how the researcher aimed to interpret the meaning of the content of the participants account rather than fix their experiences into predefined categories.

9.2   Presenting the gestalt

The process of IPA analysis of the experiences of the nurses in this study revealed a phenomena or a gestalt, a structure or experience that when considered as a whole, has qualities that are more than the total of all its parts. This chapter aims to present the component parts as a unified whole.

The nurse is a person first with their own thoughts, feelings and life experience. Together with their professional training and development layered with experiences within a professional context their sense of self and being is shaped and informed.

The nurses in this study instinctively knew when being with the dying patient was needed and invited. Saunders (1984) reminds us that nurses delivering end of life care are required to have a close involvement with the dying and be willing to accompany them on their journey. The nurses ensured a respectful presence and felt this was necessary to emolliate fear and angst of the dying and in doing so, becoming a fellow sojourner to accompany the dying on their journey towards death. Spiritual and physical closeness to the bereaved were important to the nurse. In this way, support and comfort could be offered without the need for words of consolation or condolence. Haraldsdottir (2011) warns however that time must be invested for meaningful exchanges to ensure the nurse can contextualise their care and focus on the patient. Time and resources in a busy acute setting are often lacking however and this may present a problem to the nurse in trying to deliver care to the quality and standard they feel is necessary.

Despite the difficulties presented through delivering end of life care in an acute settings the nurses inherent values and altruistic tenets ensured the nurse delivered care to the patient and their loved ones to the highest standard they could. Gerow et al (2009) describe how some nurses felt they were led by something outside their realm of knowing. The nurses in this study inherently knew what was required and how to deliver support to the dying and bereaved. They felt through delivering good care they could contribute towards a good death for the patient and they felt personally responsible for ensuring the good death was achieved. Traumatic deaths for the patient which may have been witnessed by family members intensified the feelings of loss experienced by the nurse and this loss was described as grief by some nurses and a sense of sadness by others. Mak et al (2013) concluded that some nurses delivering end of life care in acute settings often felt helpless and inadequate if they had missed chances to support the dying and bereaved due to inflexible hospital policy or lack of resources. This assertion that the nurses could not deliver "*proper nursing care*" as

described by Katz and Sidell (1999) was echoed in some of the findings from this study and contributed to their feelings of sadness and loss.

The nurses however did find difficulty in separating their personal and professional values and beliefs. This resulted in a form of professional grief and feelings of loss for their patients following their death. Papadatou (2000) suggests that relationships are invested in by health professionals and this has an impact on the grieving process following a patient's death. The process of experiencing grief caused some tension and distress to the nurses as often they perceived it was not professional to show outward signs of grief as their role was to support the dying and bereaved. The feelings of loss were occasionally intense but usually short lived. The nurses understood that they needed to acknowledge the death then let go to move on to care for the remaining patients. The final act of care was often seen as a fulfilment of their final obligation to the patient and allowed them to say goodbye. However multiple deaths may elicit feelings of grief or loss simultaneously with the feelings of preparing for the death of a patient or letting go and moving on. This may present difficulties for the nurse in making meaning of that loss while processing multiple and simultaneous episodes of grief or loss. Team support was seen as very important to al the nurses in the study and Papadatou (2000) acknowledges that whilst grieving following the death of a patient is an individual or personal emotion and experience, the opportunity for collective sharing may give further opportunity for closure.

Death anxiety and transference were often explored throughout the discussion with the nurses. It was acknowledged that a consequence of delivering palliative and of life care was a questioning of their own and their loved ones mortality. Doka (2016) also reminds us that nurses should recognise their emotional responses and transference when delivering end of life care in order to understand the base on which their humanity stands. Neimeyer (1994) describes death anxiety as the anticipation of one's own death or the fear of dying of oneself or those important to them. This view is echoed by Nyatanga (2019) who states that caring for the dying and deceased can serve as a reminder to the nurse of their own fragility which builds on their existential anxiety. The nurses sought to deal with this issue

through reflection and team support, which was described as very important, particularly following a traumatic death. The nurses felt that support from the team impacted positively on their own ability to cope with patients deaths and feelings of loss or grief. However there was no formal mechanism for clinical supervision or team support and any support was carried out informally. Formal preparation for delivering palliative care was available to the team but often nurses were trained "*on the job*" by other more senior nurses. Their views around supporting the patient and not showing emotion were sometimes in conflict with their team members.

Emotional labour is an important and often underestimated part of caring work, which describes the management of expression and display of emotions. Interpersonal relationships emerge as part of the caring process (Badolamenti et al., 2017). Bolton (2000) identified that emotional labour entails the nurse working with their emotions to ensure they appear professional. Additional acts of kindness and thought when delivering care although not seen as part of their job description was also a common trait which impacted on the interpersonal relationship and they believed that delivering care in this way was intrinsic in their identity as a nurse (Bolton, 2000). She ascertains however that the nurse cannot truly share in the grief of their patients due to the need to remain professional in their demeanour. The recognition of the existence of emotional labour and the role it plays in the emotional needs of the nurse should be acknowledged and support further opportunities for formalised reflection and clinical supervision. Sinclair (2011) suggests that repeated exposure to death may result in clinicians acknowledging death and in so doing integrate this understanding into their everyday lives which would ultimately result in normalising death and enhancing their meaning in life.

The Palliative and End of Life Care Framework document (2018) provides some guidance around education and support, however it does not address psychological and resilience aspects of delivering palliative and end of life care. A failure to acknowledge disenfranchised grief as described by Doka could result in nurses going on to develop unhealthy coping patterns (Carton & Hupcey. 2014). Doka (2016) counters this by suggesting that opportunities arise which should be recognised by organisations and individuals to offer

support to allow nurses to discuss and reflect upon their emotional reactions and concerns.

9.3 The palliative nurses experience of loss when delivering end of life care in an acute setting

The nurses in the study agreed that they did feel sadness or loss when their patient died. The loss was felt most keenly at the point of death or just after. They described trying to prepare for the death through ensuring that everything was in place to allow them to deliver good quality care. Their level of anticipation of loss increased as the time of death grew nearer. Their sense of loss sometimes reduced in the hours following death as they continued to deliver care to other patients and their families. The final act of care or last offices which entailed washing the deceased and preparing them for removal to the mortuary gave some comfort to the nurse. This was the last thing they could do for the patient and gave them a sense of completing the care and served as a final mark of respect. The feelings of loss however were often heightened during this final act of care as the nurse reflected on the loss and the care given.

Reflection sometimes occurred as a solitary process but often discussion with the team ensued to review the care delivered and the death itself. This served as a learning experience for the team and closure for the nurse.

Finally the nurse went through a process of letting go and moving on which enabled them to care for other patients and their families. In this way they felt able to care for other patients and their families without allowing the feelings of loss to become a feeling they needed to overcome or carry with them. Figure 10. is a visual representation of the suggested process of grief or loss the nurse experienced throughout the care journey. The feelings of grief or loss escalates at certain points in the patients journey and subsides as the nurse reflects on the loss and eventually lets go and moves on to care for the next patient. (Figure 10)
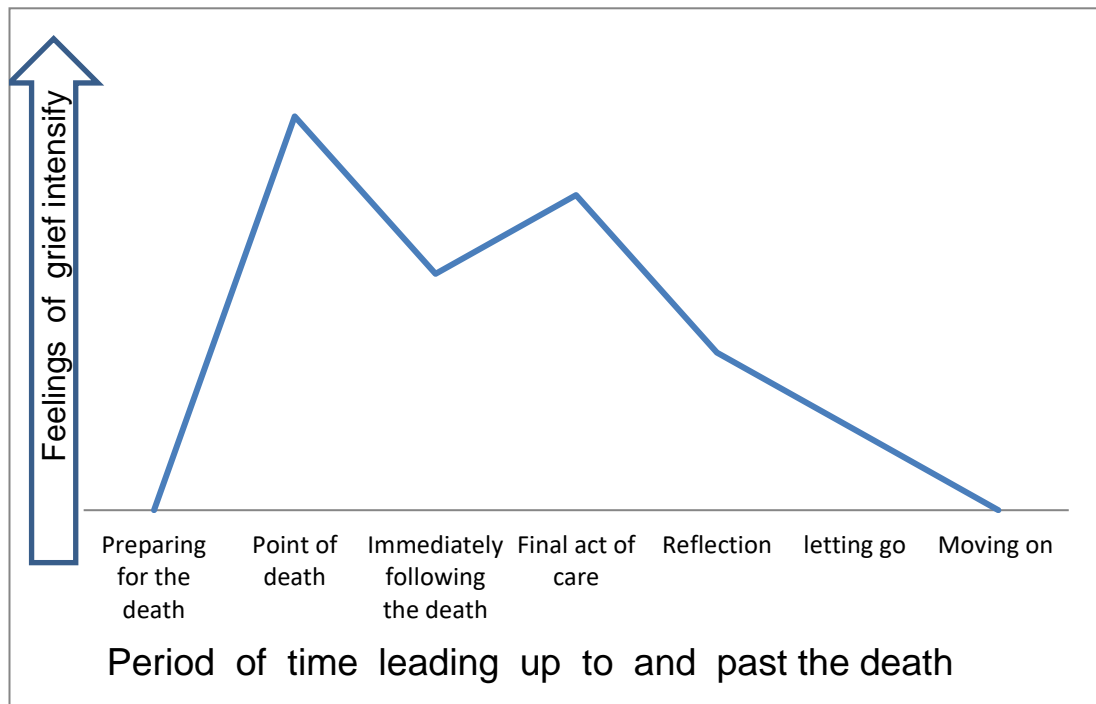
Figure 10 Palliative nurses experience of grief following a patient death

Although Figure 10. depicts a theoretical time line of loss and grief experienced by the nurse following a death, the process is not always linear as noted in other models of grief (Papadatou. 2000). The nurse may oscillate between degrees of loss and may experience different degrees of loss at different stages. The loss of certain patients and the experience of family members may resonate more closely with the nurse and the intensity and length of feelings of loss and grief may vary considerably from experience to experience. Notably, multiple deaths may elicit feelings of grief or loss simultaneously with the feelings of letting go and moving on. This may present problems to the nurse in trying to make meaning of loss.

9.4   The nurses experience of multiple deaths

According to Worden (1991) there is a limit to the number of dying patients a counsellor can work with, as an inevitable attachment will occur which will result in grief for the counsellor when the patient dies. It could be argued that comparison could be made with palliative care nurses working in an acute

setting. The potential impact of not monitoring the exposure to dying patients and their families is that the nurses could become emotionally overloaded causing distress and anxiety for them.

Papadatou's (2000) model of grief for professionals described the oscillation between experiencing grief and avoiding grief, however this was developed following a study carried out around paediatric oncology clinicians in Greece. Papadatou's model built on previous work carried out by Saunders and Valente (1994) in which they suggested that nurses could successfully manage their grief through undertaking the tasks of finding meaning, maintaining and restoring integrity, realigning relationships and managing affect. Both these models do not fully reflect the findings of this study and accurately portray the theory of professional grief that palliative care nurses in an acute setting experience. The model proposed by Papadatou (2000) focuses on the work of paediatric clinicians working in an oncology unit in Greece and similarities can be drawn but there are fundamental differences with age of patients and length of time clinicians spent caring for the patients which may impact on the development of deep and meaningful relationships and routine provision of clinical supervision for the participants in her study. The model proposed by Saunders and Velente (1994) examines oncology nurses grief and whilst there are some similarities drawn with the suggestion that nurses need to make sense of the death, manage their emotions and realign relationships. Building on this work the current study identifies some additional observations in relation to how palliative care nurses in acute settings respond to and manage their professional grief.

Previous models of grief can be drawn upon to illuminate some of the factors involved in the unique position of the palliative care nurse delivering end of life care in an acute setting. There is merit in comparing and contrasting accepted models of both professional grief and grief experienced by family members or loved ones. The model developed by Worden (1991) is used as an accepted base of knowledge and understanding. A process of contrasting and comparisons was used to develop and present new knowledge around the understanding of grief for palliative care nurses delivering end of life care in acute settings.

Worden (1991) developed a task-based approach to grief theory which is not aimed at professionals but portrays the journey the bereaved take from passive to active stages of grief. Acceptance of the reality of loss is followed by working through the pain of grief and adjusting to a new environment. Finally finding an enduring connection with the deceased while moving forward with life completes the cycle. Memories of the deceased must be maintained but the bereaved must be able to accept the loss and move on with their life. This approach describes the feelings of grief following the loss of a single person and has some resonance with the process the nurses in this study underwent, however this study identified that multiple deaths within a shift are not uncommon for these palliative care nurses and this presents layers of complexity, contributing to how the nurse makes meaning of simultaneous and cumulative loss and moves on.

As Figure 10 is a representation of the process of grief or loss the nurse experiences for one patient, to further expand on this illustration it is necessary to understand the impact of multiple deaths, sometimes within a short time frame. The nurse may be moving on and letting go following the death of one of their patients only to be faced with the need to prepare and make meaning of another patient approaching death within the same time frame .

Developing this new observation arising from this study Figure 11 presents an illustration which depicts the journey the nurse may undertake as multiple patients die as the nurse continues to deliver care to other dying and deceased patients within their care. They simultaneously manage wanting to prepare for the death, experiencing grief and loss at the moment of death, navigating their own acceptance, and finally reflection and moving on. This presents opposing states of understanding and meaning making for the nurse which could cause further distress and anxiety.
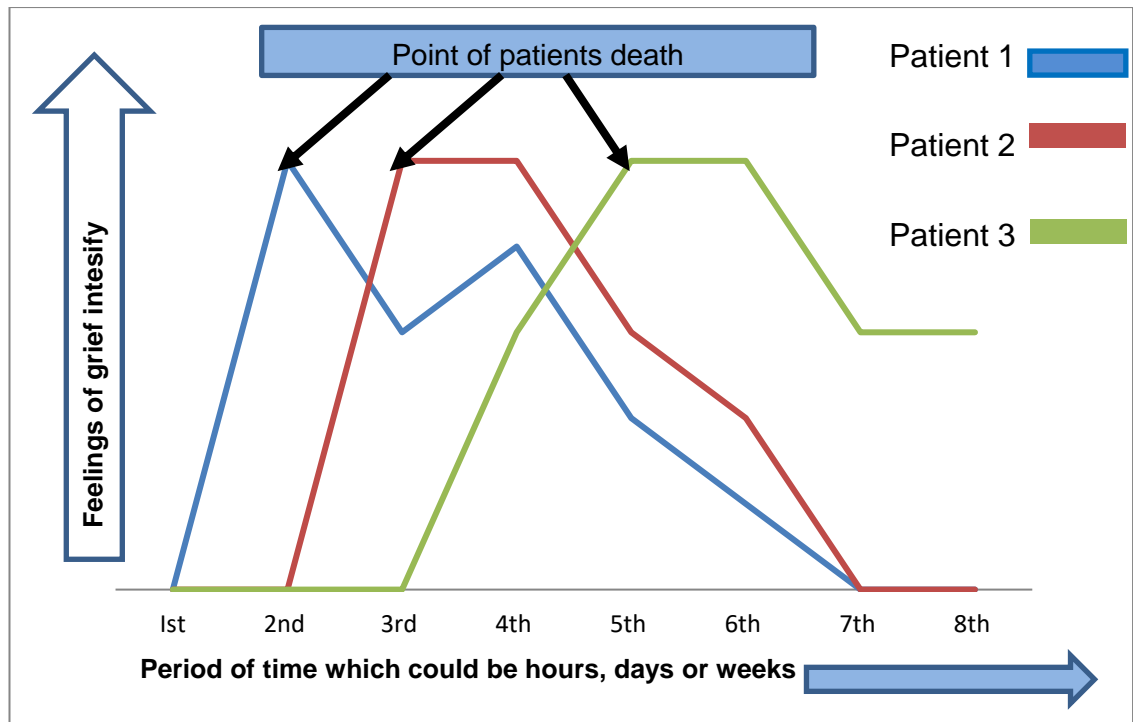
Figure 11 palliative care nurses experience of grief following multiple deaths

9.5 New knowledge, presented as a proposed visual representation of grief for palliative care nurses delivering end of life care in acute settings.

After completion of analysis of the findings, the phenomenon of nurses grief started to emerge throughout the discussion chapter, which led to an observation of the similarities and differences of the revealed phenomena against accepted models of grief. As previously discussed there are many different models of grief and this study did not aim to develop a new model. Worden's (1991) task based model of grief however did loosely overlay the states of being the nurses in this study demonstrated and described. To this end, the illustration of the palliative care nurses experience of grief when set within the framework of Worden's (1991) task-based model of grief could be used to understand and illustrate a new understanding of the stages of nurses grief. The states of being experienced by the nurse travel from accepting the loss, experiencing the pain, letting go or withdrawing and finally reinvesting in delivering care to the remaining patients. The

experience of grief or loss may differ from patient to patient and result in several layers of complex feelings and emotions. The nurses undergo progressive states of being and understanding and these are described in the next section as preparedness, experiencing loss, making meaning and letting go and finally moving on.

9.5.1 Preparedness

Task one of Worden's (1991) model is accepting the reality of the loss. This stage of preparedness presented here is the stage leading up to the death which includes the nurse accepting and preparing for the death and ensuring everything is in place and the dying and bereaved are fully supported. The act of being with the patient and their loved ones as death approaches is an important component of delivering good quality care. The nurse viewed their involvement as not just a nurse but another person sharing the journey with the bereaved or patient - offering a compassionate and humane approach. The nurse offers physical and spiritual closeness to the bereaved and support and comfort through presence and knowing rather than words of consolation or condolence. Often taking the role as fellow sojourners in their hour of need.

The ultimate aim was a good death for the patient and the nurses believed that support for the patient and loved ones was an intrinsic part of their role. They wanted to create a safe space for the dying patient. This could be achieved by being prepared to manage physical deterioration that may require medication and understanding the dynamics of the approaching death physically, spiritually and psychologically.
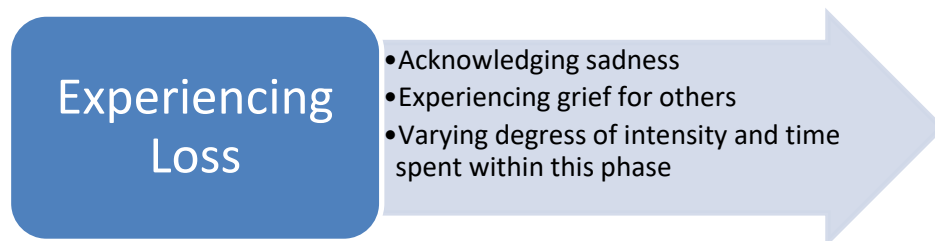

Preparedness
- Ensuring anticipatory medication is prescribed and available
- Ensuring support for patients, families and colleuges is available
- Being able to "be with" those in need
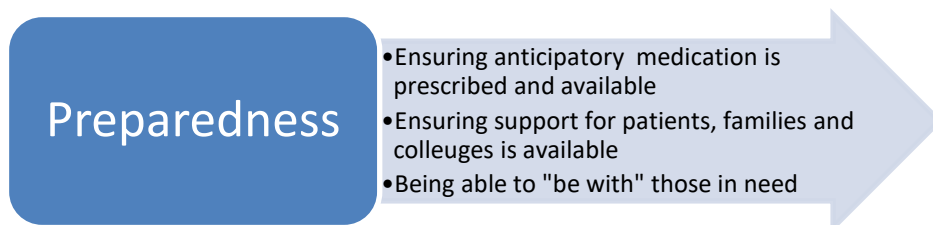
Stage 1 of process undertaken – Preparedness

9.5.2 Experiencing Loss

Worden's (1991) second stage is experiencing the pain of grief. This proposed representation of nurses grief illustrates the second stage of experiencing loss and the pain of grief. Feelings of loss and grief by the nurses often peak at the point of death. The nurse acknowledges the death and sometimes experiences feelings of grief or loss which may be intense but are usually short lived. These feelings can resurface during delivering the final act of care or last offices or contact with the family when they return to collect the death certificate. The relationship with the patient and their loved ones was given high importance with the level of connection depending on several factors. The length of time the nurse knew the patient or loved ones and the association the nurse had with them impacted upon the level of bond they felt. This then contributed to the nurses feeling of loss or grief following the death. The nurses explained that they would often grieve in private away from the bereaved loved ones. Worden (1991) however suggests that healthcare professionals should practice active grieving. They should allow themselves to experience the sadness and grief after patient dies. Bolton (2000) describes the process of trying to present a professional demeanour as emotional labour.

Emotional labour is an important and often underestimated part of caring work and the recognition of the existence of it plays a basic role in ensuring the emotional needs of the nurse are met (Badolamenti et al. 2017).
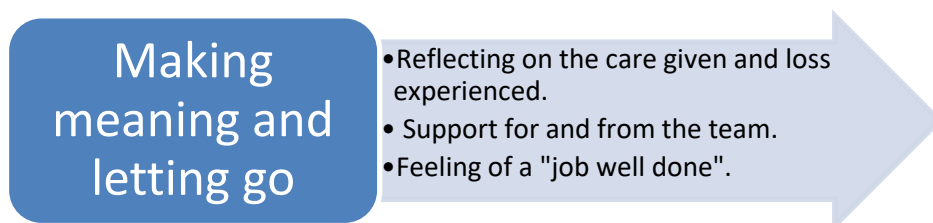

Experiencing Loss
- Acknowledging sadness
- Experiencing grief for others
- Varying degress of intensity and time spent within this phase

Stage 2 of process undertaken – Experiencing loss

9.5.3 Making meaning and letting go

The third stage of Worden's (1991) model is adjusting to the environment in which the deceased is missing. This representation of the nurses journey depicts making meaning and letting go, they adjust to the environment in which the patient has died. Reflection with or without the team, team support and feeling that they could rely on their team to understand their experiences and also share and exchange knowledge. All these actions contributed to the feelings of loss and grief subsiding.

Throughout the interviews carried out in this study the nurses discussed reflection in relation to many different topics. All the nurses concluded that reflection was a very powerful tool to manage their emotions, make sense of events and improve their resilience. It was described as empowering and helped to counteract the negativity and sadness which sometimes surrounded death. The death of an elderly patient who had experienced a good death was accepted as the natural order of things and the nurse felt they had delivered care to the best of their ability. Relief was sometimes felt after a patient died. The nurse felt that the cessation of pain and anxiety for the patient and the bereaved was achieved and the nurse was relieved that the patient was finally at peace. Carrying out the final act of care was perceived as the final mark of respect and allowed the nurse to say their goodbyes. Finally the nurse reminded themselves that they had delivered care to the best of their ability and felt it was a job well done. If the nurse felt unprepared or did not have the confidence or competence to deliver good quality end of life care then their feelings of loss and sadness were heightened.

Making meaning and letting go
- Reflecting on the care given and loss experienced.
- Support for and from the team.
- Feeling of a "job well done".

Stage 3 of process undertaken – Making meaning and letting go

9.5.4 Moving on

The final stage for Worden's (1991) model is to find an enduring connection with the deceased while moving forward with life. The final stage in this illustration of the palliative care nurses journey is that of moving on and the feelings of loss returning to baseline. The nurses used the experience of delivering end of life care as an opportunity to improve the care delivered to subsequent patients and in so doing fostered an enduring connection with all their past patients as a mechanism for improving care moving forward. The nurse then felt ready to return to the role of caring for the dying and deceased again. The nurses returned to shift the next day and viewed it as a new day with new patients who need the nurse to continue to give good quality care. The memories of the experience surrounding certain patients death may stay with the nurse with positive or negative connotations however generally they tried to put negative thoughts to the back of their mind, enabling them to commit fully to caring for new patients and their families. The enduring connection the nurse experiences is dependent on the perceived quality of death for the patient and the bereavement and anticipatory grief experiences of the attending family.

Moving on

- Tomorrow is a new day
- My other patients need me to continue to care for them
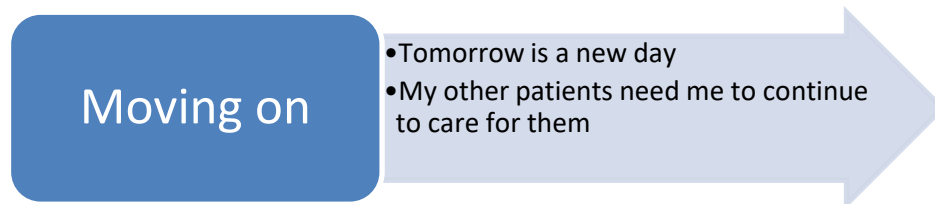
Stage 4 of process- Moving on

9.5.5 The iterative process of how nurses make meaning of grief and loss in an acute setting.

As all proponents of grief theory are quick to point out, grief is not a linear process nor are there set timeframes (Worden, 1991. Saunders and Valente. 1994, Schut. 1999, Papadatou. 2000). A nurse may experience loss and continue to feel emotions of grief or sadness for a longer period of time for

certain patients whilst quickly moving through the stages illustrated. As discussed in the previous section multiple deaths may result in the nurse undergoing multiple, layered and complex emotions. The illustration below brings all the stages together to demonstrate an often reported sequence of thought, feelings and emotions together with actions such as preparing anticipatory medication and speaking to the patient and the soon to be bereaved. Theses stages or sequences are all experienced by the palliative care nurse whilst delivering end of life care in an acute setting. The nurse may progress through the stages as described previously but as Figure 12 highlights the potential for the nurse to move across and between non sequential stages intermittently or iteratively.

Preparedness
•Medication
•Support
•being with

Moving on
•A new day
•My other patienst need me

Experiencing Loss
•Sadness
•Grief
•Intensity

Making meaning and letting go
•Reflection
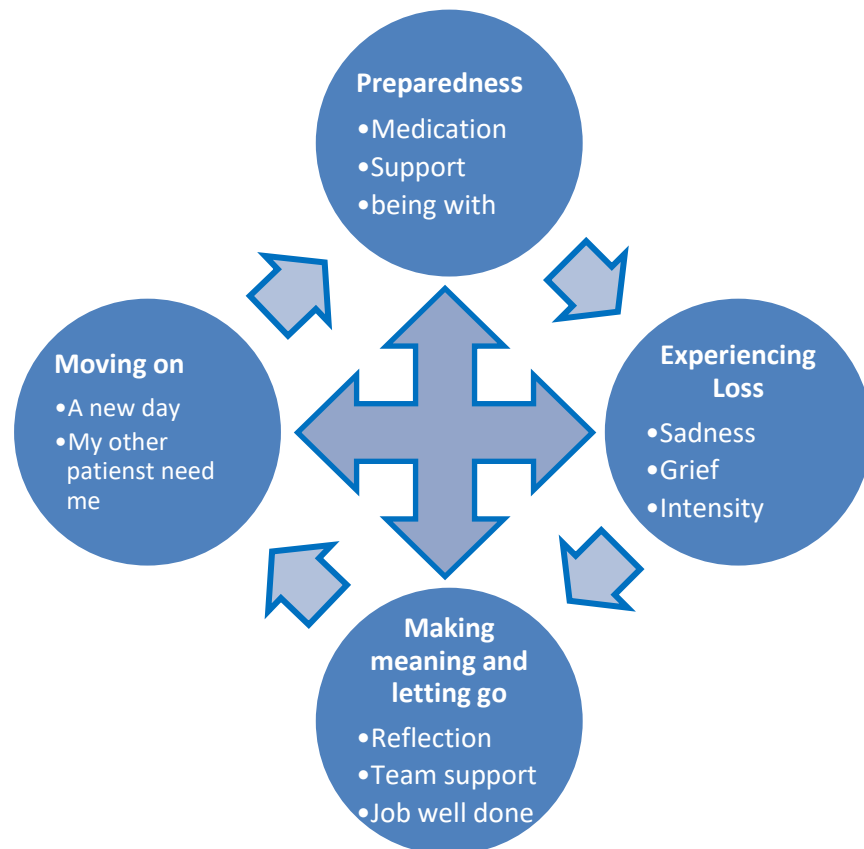•Team support
•Job well done

Figure 12 – Visual representation of process of professional grief for palliative care nurses delivering care in acute setting

9.6   Mitigating the nurses feelings of sadness and loss.

Whilst the four stages have been discussed in detail it is important to explore the factors which can and do impact on the palliative care nurses ability to progress through the stages with a positive way, from a place of understanding and knowledge. There are factors which can and do mitigate the nurses feeling of sadness and loss and theses should be explored and expanded upon.

9.6.1 Confidence and competence

The first stage of being prepared requires a good grounding in palliative and end of life care delivery. The nurses in this study who had more experience of palliative and end of life care generally felt more prepared. They understood what may be required not only in regards to medication but support for the patient and the bereaved. This

Confidence and competence are linked and together form a powerful base to equip the nurse to deliver good quality care whilst managing their own thoughts and emotions. They are safe in the knowledge that they know how to care for the dying and feel confident to deal with any challenging situations as they arise. Education and support from the organisation are necessary to ensure the nurse feels supported and able to carry out the task of caring for the dying to the best of their ability (Jack et al,. 2004, Scottish Government. 2008, O'Hara. 2011, White & Coyne. 2011, NES. 2018)

A important finding from this study was that a feeling of being unprepared for the death added to the nurses emotional distress.

9.6.2 The power of reflection

The third stage of making meaning and letting go was supported through the use of reflection as discussed in the previous section. The nurse was able to foster resilience through shared experiences and support from colleagues. This helped to mitigate their fears and feelings of loss. The nurses felt that delivering the best care they could to ensure the patient achieved a good death enabled them to make meaning of the death and move on. This

enabled them to continue with caring for others who were dying. The nurses did concede that they did experience grief or sadness, but they were wary of allowing themselves to get too deep as they would then enter into a grieving process and not be able to move on and look after the remaining patients.

All the nurses who participated in this study thanked the researcher for allowing them to be part of the study. They stated that through taking part and being asked about and able to tell their story in their own words they felt a form of relief. Two nurses stated that they had never been asked about their feeling previously and found it beneficial to explore their own emotions and thoughts around the death of their patients. Most of the nurses stated that the discussion had helped them, even though some difficult emotions were brought to the surface they felt that talking about them had allowed them to process their thoughts and emotions which they had kept hidden.

Clinical supervision and reflection are readily available and encouraged amongst nurses delivering care in hospice settings however there is a distinct lack of formal supervision for nurses delivering end of life care in acute settings. This may have a detrimental effect on their emotional wellbeing. Reflection and clinical supervision should be part of the education programmes and support offered to all nurses at the start of their training but also throughout their practice and is explicitly required according to Luxardo (2014). Many others also counter that not only reflection and clinical supervision are important , but team support contributes to the wellbeing of the individual clinician but the cohesion of the team as a whole (Doka. 2014; Frances & Bulman. 2019; Goodrich. 2015; Lopez. 2006; McClosky & Taggart. 2010; Papadatou. 2000).

9.7 Presenting the summary of new knowledge gained on how palliative care nurses in acute settings make meaning of loss and death when delivering end of life care

Nurses are sentient thinking beings whose lived experiences and feelings affect their thoughts and emotions. This in turn impacts not only on their personal life but also their professional identity and perceptions of good quality care. The processes they enact shapes and informs their understanding of the world and their experiences therein. The work of a palliative nurse in an acute setting who delivers care to the dying and deceased entails entering into an intimate relationship and shared space with the patient and the bereaved, a position not often encountered by other health care professionals. The nurse instinctively knows when being with the dying patient is needed and invited. The act of respectful presence is necessary to ease the suffering and accompany the dying on their journey towards death.

Their inherent values and altruistic tenets move the nurse to deliver good quality care which would contribute to a good death for the patient and they feel personally responsible for ensuring this was achieved. Through being prepared both physically and emotionally they felt that they helped to achieve a good death for the patient and eased the suffering of the newly bereaved. Support for the patient, bereaved and fellow team members played an important part in their act of care giving and mitigation of their own feelings of loss.

Often the nurse reported that they did find difficulty however in separating their personal and professional values and beliefs but did experience grief and feelings of loss for their patients following their death. This caused some tension and anguish to the nurses as often they perceived it was not professional to show personal grief as their role was to support the dying and bereaved. The feelings of loss were sometimes intense but often short lived as they needed to acknowledge the death and let go to move on to care for the remaining patients. Death anxiety and transference were

consequences of delivering palliative and of life care which the nurses sought to deal with through reflection and team support.

This chapter presented the gestalt and conclusion arising from the previous findings and discussion chapter. The themes that were revealed aligned to various previous research carried out across many disciplines within the healthcare setting to various degree. There is no evidence however of the insight into palliative care nurses in acute settings grief. Following the drawing together of all the themes discussed within chapter 8 an illustration depicting a visual representation of the process of professional grief was presented. The process identified four stages of preparedness, experiencing loss, making meaning and letting go and finally moving on. Similarities were drawn from Worden's (1991) work on a four stage model grief theory however the process is not linear or even cyclical as oscillation between phases of grief can and do occur as noted by Papadatou (2000).

Each nurse is an individual with their own experiences which impact on their understanding of grief and how they make meaning of loss and death in such conditions is dependent on many factors. Recurring themes and insights are drawn from this research and are presented as a unified whole to illustrate and illuminate the story of their grief.

This study identified that the nurses that deliver end of life care in acute settings in Scotland have unmet needs and experience persistent grief with little or no formal support.

Chapter 10
Recommendations for Future Practice

10.1   Introduction

This chapter brings the thesis to a close by discussing the recommendations for future practice, dissemination of findings and further research requirements. Reflection on the process undertaken to construct and carry out the study and complete the thesis is discussed and finally a review of the limitations of the study is presented. It is useful however to re-visit the themes identified throughout the study and use figure 13 as a framework within which to position the implications and recommendations for future practice.
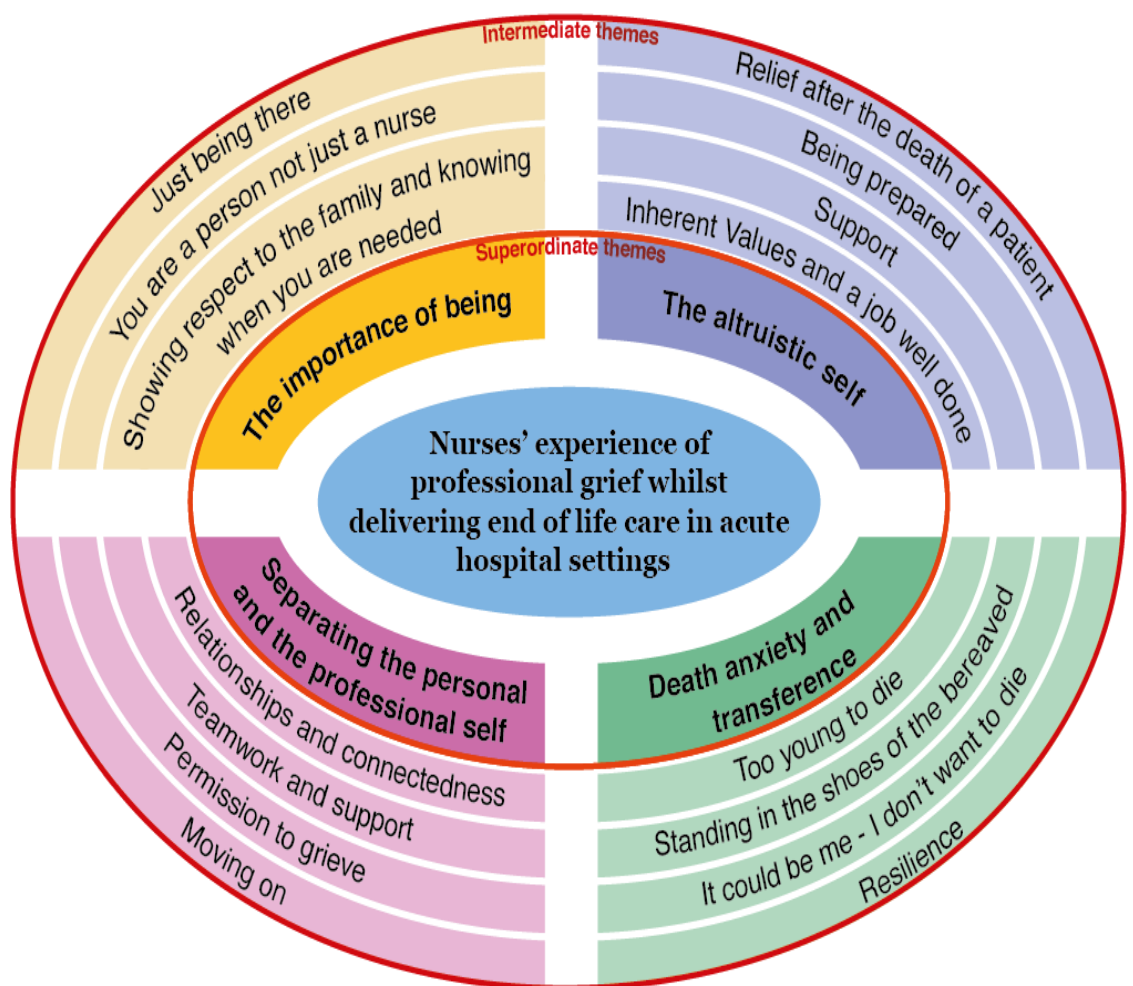

Figure 13 Presentation of themes around nurses grief

10.2 Implications and recommendations for future practice

The scoping review did not identify any previous studies carried out in the UK which examined how palliative care nurses delivering end of life care in acute settings, make meaning of loss and death. Whilst the findings from this study are specific to the nurses within this ward, the themes that emerged were comparable to findings and discussion points in many other studies with similar themes and research questions. In order to ensure the needs of the palliative care nurse delivering care in acute settings are managed and understood, a set of actions could be undertaken to improve the burden of emotional labour experienced by this professional group. The suggestions to improve future practice however, could and should be applied to all health care professionals, facing death and dying on a regular basis.

a. It should be acknowledged that nurses delivering end of life care do experience a form of grief albeit often short lived which could result in unmet needs which leads them to experience persistent grief. Feelings of loss can be intense at times and can be linked to death anxiety and transference.

b. The visual representation of the suggested process of grief or loss the nurse experienced throughout the care journey (Figure 12 pg 259) could be used as an indication of the emotions a nurse may experience as they deliver end of life care.

c. The nurse may be providing care for many patients who are close to death simultaneously. This situation may lead to the nurse oscillating between degrees of loss and reflection and moving on at different stages. Figure 11,page 254, depicts the grief or loss process when multiple deaths are experienced simultaneously or within a short time frame and could be used to illuminate the duality of feelings experienced, which may present problems to the nurse in making meaning of multiple losses. The illustration could be used for future education or reflection and clinical supervision sessions.

d. A visual representation of the process of professional grief for palliative care nurses delivering care in acute settings is presented in Figure 12, page 258. This representation of new knowledge combines

Worden's task-based model of grief with the findings from this study to develop an understanding of the stages of accepting the loss through to withdrawing and reinvesting, for palliative care nurses delivering end of life care in an acute settings. This could be used to further understand the complexity of feelings experienced.

e. These visual representations of nurses grief presented in chapter 9 acknowledge that nurses experience of grief and multiple deaths could result in nurses having difficulty in making meaning of loss and death. They could be used as discussion points and teaching aids when delivering palliative and end of life care education to nurses or other health care professionals. Robust nursing educational programs which incorporate not only clinical aspects but psychological elements also should be offered to nurses. The education framework developed by NES should be complimented by development of skills in emotional intelligence (NHS Education for Scotland (NES. 2018). Badolamenti (2017) describe emotions management as a unique and specific skill in nursing and one that is often unappreciated. A full suite of strategies can be provided to equip the nurse with the necessary skills to deliver good quality palliative and end of life care and to manage their own needs and emotions.

f. The representations could also identify why and when nurses require formalised clinical supervision. Reflection and clinical supervision should be part of the education programmes offered to nurses not only at the start of their training but more importantly throughout their practice. Hospice UK (Goodrich. 2015) assert that hospice staff need to be actively supported in order to reduce risk of compassion fatigue and reduce levels of stress. The same assertion should apply to palliative care nurses delivering end of life care in an acute setting and it could be argued that all nurses facing death and dying on a regular basis should have access to reflection and clinical supervision. Team leaders should ensure clinical supervision is routinely in place and restorative supervision and support for distressed and burnt-out clinicians should be available when required.

The nurses in this study did not have access to clinical supervision and reflection occurred privately or reactively as a team following a difficult period of practice. Lopez (2006) suggests that professionals in end of life care experience difficulty in separating their worlds from their patients worlds and should therefore be offered clinical supervision to help separate the two.

Nurses delivering end of life care experience a whole array of thoughts and feelings and undergo often very different experiences of the process of professional grief. However, in conclusion, understanding, empathy, help and support for nurses delivering end of life care should be a key component of any organisation tasked with delivering care to the dying.

10.3 Dissemination of findings

The study findings will be disseminated locally within NHS Borders through presentation and teaching sessions with nurses and nationally through posters and applications to present at national conferences. The findings will also be available and be held on the data base of the Scottish Palliative Care Research Network allowing access to members of the network. There is an intention also to present to the NHS Board Bereavement Coordinators / Strategic Leads and any other forum with significant and relevant subject matter.

10.4 Further Research

Whilst the study provides insight into the experiences of palliative care nurses delivering end of life care in acute settings within this study site it also provides a starting point to test the development of the representations presented here within other settings. Further research is required around resilience and nursing patients at end of life, particularly in the Scottish context. As stated previously no research pertaining to this subject area has been carried out in Scotland in the last ten years at least. Further work is required if we are to ensure palliative care nurses and other nurses

delivering end of life care in acute settings are supported and cared for, to not only nurture and develop our nurses but also to improve the quality of end of life care we deliver to the people of Scotland.

10.5 Reflections on the study, PhD and resubmission

The initial thoughts around embarking on this professional doctorate degree were those of expectation and anticipation together with a large amount of trepidation. As a very enthusiastic but novice researcher I questioned my skills and ability to conduct research to a high standard and then convert the data into something meaningful and relevant to my practice.

I developed confidence as a researcher through the taught modules during the early years of the programme but by far the biggest impact has been the support, discussions and mentorship I have received from all the supervisors in my team from the first proposal submission to the completed thesis.

The journey of conducting research, analysing the data, discussing the findings and completing this professional doctorate degree has been exciting, thought provoking, emotional and inspiring in equal measures.

Once the interview stage commenced and I started to speak with the participants I quickly realised the depth and breadth of the data that was being gathered. The interpersonal trust that was present in each of the interviews produced some very though provoking and emotional discussion. The participants were happy to share their thoughts and concerns with me as they saw me as "one of them", I had credibility not only as a palliative care nurse but also as a researcher and academic who would honestly and compassionately describe how they made meaning of loss and death in a professional context in order to improve practice and support nurses going forward.

The analysis stage presented some challenges due to the volume, breadth and depth of the data gathered. The support from my supervisors however guided me through the early stages and steered me towards understanding and confidence in interpreting the data.

My first submission of the thesis and subsequent Viva did not result in a pass and I was asked to make major amendments and undertake a second Viva. Initially I was disappointed and felt my earlier confidence erode as I started to question my validity as a researcher and PhD candidate. I took some time away from my research to allow space and focus for the effort involved for resubmission.

I had already experienced personal grief with the loss of my mother during the original completion of the thesis but encountered personal grief for a second time when my father became ill and died whilst I was in the process of developing the thesis further for the second submission. This resulted in a delay again as I grieved the loss of my father. Once I was ready to resume and started working on the thesis however, I became aware of a deeper level of understanding of the differences and similarities of personal and professional grief, leading to illumination of some further themes which may have otherwise remained hidden. The issue of death anxiety and transference became clearer as I revisited the transcripts. It became even clearer that nurses are people to, with thoughts and emotions which impact on and inform the care they give.

Following the delay in completion due to personal grief I also experienced a further delay due to the impact of the Covid 19 pandemic. I was redeployed from my Quality Improvement Facilitator role to work clinically alongside the nursing teams delivering care on the Covid wards throughout the first, second and third wave. The work was emotionally and physically draining but presented an opportunity to observe some of the findings in action that I had gleaned from the analysis already carried out from this study. Many of the nurses pulled together to work on the Covid wards did not have a great deal of experience caring for the dying, particularly in such unpredictable and frightening circumstances. These very circumstances polarised the stages portrayed in the visual representation of process of professional grief for palliative care nurses delivering care in acute setting, discussed in the previous chapter. The nurses felt unprepared, they acutely felt the loss of patients, particularly as visitors were not allowed and the nurse became the carer and comforter to the dying patient. Making meaning and letting go was often difficult but good team support helped with this process. Finally moving

on to care for other patients was necessary due to the increasing number of Covid cases and the need to manage and care for a quickly growing patient cohort. This experience illuminated yet further connection and insight which contributed to the revision process.

The experience of completing the thesis was woven throughout with reflexivity. This has been described earlier in thesis as ensuring that the researcher thinks critically about what is being researched and written. The engagement with the participants, data and one's own experiences led to a double hermeneutic approach. The description by Smith et al. (2009) of the process of undertaking the interviews within IPA as a "conversation with a purpose" really captured the context and depth of shared experiences.

A further component of reflexivity however was the whole experience of the journey, from the very first curious conjecture around nurses grief to final proof read and submission of the thesis.

The life experiences described above gave me the opportunity to revisit my analysis from a different perspective and I developed a deeper level of understanding of the issues of grief discussed throughout the interviews.

The required amendments allowed me to give more structure and precision to the document which I feel enables the reader to clearly navigate the process undertaken and make sense of the findings and recommendations. I engaged with the constructive criticism and believe the resulting thesis is much more concise and coherent and tells the true story of nurses grief. I describe the experience of undertaking the PhD as a journey. I feel I have grown as a person, a nurse and a researcher through conducting this study, the iterative process of review and refinement and eventual presentation of the thesis. I am very excited to share the findings with the wider palliative care community.

 I aim to continue as a practitioner – researcher and hope to contribute in a positive way to the development and delivery of good quality palliative and end of life care going forward.

Grief is not mutually exclusive for the loved ones of the deceased but can touch all who hold a relationship with the dying patient and I feel this thesis

clearly articulates the processes nurses undergo when delivering end of life care. It is indeed our grief to have…

10.6 Limitations of the study

The nature of the subject and the design of the research question required selection of a methodology that would allow the researcher to achieve a clear picture of the nature of social reality and the phenomena of grief experienced by palliative care nurses delivering end of life care in an acute setting. Qualitative approaches which are derived from interpretative traditions therefore appear the best fit for this type of research. The researcher however, must be cautious in assuming one methodology above another has credibility and integrity,

Following analysis of the philosophical assumptions and world views of the researcher of social constructivism a phenomenological approach was deemed to be the best fit. A SWOT analysis identified that phenomenology was a credible methodology to use in studying consciousness in nursing which allowed analysis of the meaning being lived by participants in the study. It is a method of enquiry which aims to examine and explore and eventually understand the participants' everyday experiences.

Interpretative phenomenological analysis (IPA) was developed by Smith et al (2009b) and has its base in psychology however it is increasingly being used in other disciplines such a social, human and health sciences. It is qualitative research approach used to examine how participants make meaning and sense of their life experiences. Smith et al. (2009b) describe the IPA researcher as open-minded with patience, flexibility and empathy. They must also be willing to enter the world of the participant and respond to the participant within the context of their world. To this end, IPA was chosen as the approach to take for this study.

One concern of using this approach is the researchers subjectivity but this could be viewed as an opportunity as it may be used to inform analysis of

the data and retrospective descriptions which may contain errors but also more accurately reflect the way situations were experienced or remembered. The researcher must also endeavour to strive to get to the truth and not impose their own explanations on the phenomena before they have been understood from within.

The most frequently used method of sampling for qualitative research is purposive sampling which is a method of selecting participants which are knowledgeable about the subject under study and assumes the researcher has knowledge about the population from which the participants are selected. A criticism of this method of sample selection could be that there is no external or objective method for assessing how representative the subject group is (Polit et al., 2001). The researcher chose this method as the inclusion criteria was for palliative care nurses working in an acute setting. This group of participants by default had knowledge about the subject under study. The researcher did have knowledge not only of the population from which the participants were selected but also the subject under study as the researcher had previously worked alongside the team within the ward as a staff nurse. This closeness to the subject matter and close relationships with the participants of the study could have resulted in closed conversations with the participants reluctant to share their innermost thoughts and feelings. The outcome however did not reflect this as the researcher had first-hand experience of the issues they faced on a daily basis. The researcher was viewed as an insider with credibility to fully understand the explicit and implicit description and meaning making of caring for patients approaching death.

This study was carried out in one small palliative care ward in an acute setting in semi rural Scotland. Relationships and interdependencies between staff, patients and relatives may be different in larger urban hospitals and other areas of the country. This may impact on the results of a similar study carried out in a different location.

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Appendix 1 Early Policy Documents

1. Our National Health : A Plan for action, a plan for change (Scottish Executive, 2000) was published aiming to achieve a step change in the modernisation of the NHS in Scotland. A promise was made to launch a National Leadership Development Programme in 2001 to deliver these changes. The report suggested that palliative care was mostly associated with cancer and that it must be widely available to any and all patients who need it. The report went on to say that the government would support palliative care services and that the Clinical Standards Board for Scotland and the National Care Standards Committee would produce standards for palliative care. No detailed action plan or recommendations were included in the report.

2. In 2001 the *Cancer in Scotland: Action for Change* (Scottish Executive Health Department, 2001) report outlined the steps required to develop and improve cancer services within Scotland from 2001 onwards. The provision of palliative care remained a critical component of the report but acknowledged that whilst palliative care was extremely important in cancer care it was not exclusive to cancer care. It also acknowledged that there was a lack of understanding of the principles of palliative care amongst health professionals and that organisations responsible for providing training and education for health professionals should include palliative care principles in their curriculum and ensure their graduates had a clear understanding of the principles. They also note that by March 2002 all NHS boards in Scotland should have produced a comprehensive needs assessment for palliative care. The Review of Palliative Care Services in Scotland report carried out in 2008 found that all but two boards had achieved this (Audit Scotland, 2008). No detailed action plan or recommendations for the delivery of palliative care were included.

3. *The Coronary Heart Disease and Stroke: Strategy for Scotland report* (Scottish Executive 2002) was the culmination of four years of research by the coronary heart disease and stroke Task Force and

based on consultations with patients, clinicians and healthcare managers. The report references palliative care as a service which should be made available to those with end-stage heart failure. It did not have any detail around palliative care delivery but echoed the previous reports stating that palliative care should be available to all patients with progressive incurable conditions. They also reported that The Scottish Partnership for Palliative Care had compiled a working group to examine those issues (Scottish Executive, 2002) . By 2005 the *National Framework for Service Change in the NHS in Scotland: Care in local settings* had been published and highlighted that palliative care delivered in the home setting would reduce hospitalisation within the last three months of life through the delivery of co-ordinated palliative care (Care in local settings Team, 2005).

4. In 2005 *Delivering for Health* was published, an action plan for the changes required to meet the health care requirements of a changing demographic and population. The main tenants of the report relating to palliative care promoted a shift in the delivery of care away from main acute hospitals to community hospitals or within the patient's home resulting in a reduction of emergency admissions for unscheduled care (Scottish Executive, 2005) .

5. *The Future Care of Older People in Scotland* report published in 2006 called for further investment to improve the provision of palliative care in Scotland and the recommendation to build on the success of the Gold Standards Framework for community palliative care and that the effectiveness of end of life care initiatives should have full evaluation (Scottish Executive, 2006).

6. The Gold Standards Framework developed by Dr Keri Thomas in 2000 as an initiative to improve palliative care within a primary care setting. The organisation is a not for profit organisation and provides evidence based best practice models for delivery of high quality palliative and end of life care and provides training and accreditation within a number of settings within the UK and internationally (National Gold Standards Framework Centre, 2015).

Appendix 2 Strategic Framework for Action on Palliative and End of Life Care

Strategic Framework for Action on Palliative and End of Life Care - Executive Summary

Vision
By 2021, everyone in Scotland who needs palliative care will have access to it.

Palliative and End of Life Care Aims
- Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.
- People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences.
- Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.

Palliative and End of Life Care Outcomes
- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

Palliative and End of Life Care Objectives
We will achieve this by:
- Improved identification of people who may benefit from palliative and end of life care.
- An enhanced contribution of a wider range of health and care staff in providing palliative care.
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed.
- A greater openness about death, dying and bereavement in Scotland
- Recognition of the wider sources of support within communities that enable people to live and die well.
- Greater emphasis in strategic plans, research activities and improvement support programmes on enhanced access to and quality of palliative and end of life care.

Appendix 3 Information Sheet

Edinburgh Napier
UNIVERSITY

Information for registered nurses.

"It's not our grief to have" – a study of the attitudes and beliefs of the phenomenon of grief experienced by palliative care nurses when delivering end of life care in a Palliative Ward.

My name is Gerry Finnan and I am a Staff Nurse with NHS Borders and a PhD student from the school of nursing midwifery and social care at Edinburgh Napier University. I am undertaking a research project for my thesis titled "It's not our grief to have "– a study of the attitudes, customs and beliefs of the phenomenon of grief experienced by palliative care nurses when delivering end of life care in a Palliative Ward.

The study will investigate the lived experiences of nurses who are frequently exposed to dying patients and death in the course of providing nursing care. The concept of "professional grief" will be examined. Areas such as the personal feelings of nurses around grief for their patients and the families, questions such as are they allowed to grieve will be discussed and observations made of the way in which they approach this question . Models of grief will be explored and compared and contrasted to identify if there are any similarities between grief as an accepted phenomenon and the grief experienced by nurses. Characteristics of the nurse will be considered together with the organisational paradigm and accepted views of society.

The findings of the study will be shared with the Palliative Care clinical team to inform future education/training requirements to improve the experience of the palliative care nurse and improve delivery of end of life care.

I am looking for volunteer Charge Nurse and Staff Nurses from the Palliative Care Unit to participate in the study. If you do agree to participate you will agree to be observed by the researcher as you carry out your care delivery and may be asked to take part in semi structured interviews to elicit thoughts and perceptions of process of delivering care. Field notes will be taken throughout and observations carried out of care delivery and interaction with

patients and colleagues. If you do agree to participate a consent form will be given to you which you will be required to sign and return to me at the Margaret Kerr Unit within 14 days.

All data will be anonymised and identification will be replaced with a number. All data collected will be kept in a secure place. This will be a stored on password protected computer and hard copies kept in a locked cabinet in the researchers office at Edinburgh Napier University. This data will be kept until the end of the examination process and then destroyed. The results may be published in a journal.

If you would like to contact an independent person, who knows about this study but is not involved in it, you are welcome to contact Gerri Mathews-Smith from Edinburgh Napier University. The study supervisor for this audit is Barbara Neades and all contact details are noted below. If you have read and understood the information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now complete the consent form and return it within 14 days to Gerry Finnan at the Margaret Kerr Unit BGH.

I would like to thank you for your interest in this study and findings and recommendation following completion of the study can be forwarded to all participants after the study is completed.

Yours sincerely

Gerry Finnan

Gerri Mathews-Smith - Independent advisor

School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN
Tel : 0131 455 5615

Barbara Neades– Study supervisor

School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN
Tel: 0131 455 5315

Appendix 4 Consent Form

Consent form

"It's not our grief to have " – a study of the attitudes and beliefs of the phenomenon of grief experienced by palliative care nurses.

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: _____

Signature of participant: _____

Signature of Researcher: _____

Date: _____

Contact details of Researcher

Name of Researcher: Gerry Finnan

Address: Margaret Kerr Unit,

                        Borders General Hospital.

Email: Geraldine.Finnan@borders.scot.nhs

                        or

                        09013046@live.napier.ac.uk

Appendix 5 Interview Schedule

Edinburgh Napier
UNIVERSITY

Interview Schedule - "It's not our grief to have" – How palliative care nurses make meaning of loss and death when delivering end of life care

Time of interview: Date: Place:

Interviewer: Interviewee: Pseudonym:

Questions:

1. What drew you to work in palliative and end of life care?

- o How long have you been qualified?
- o Where have you worked previously?
- o What attracted you to work in PC?
- o Do you want to stay working in PC and if so why ?

2. What thoughts and feelings do you experience leading up to and after the

death of a patient?

- o Have you experienced patients dying on the unit ?
- o What feelings and thoughts do you have leading up to death ?
- o Have you been present at time of death ?
- o How did you feel at this point ?
- o What thoughts did you have immediately after the death ?
- o Did you continue to think about the experience or patient after death ?

3. How do you manage positive or negative thoughts and feelings after the

death of a patient?

- o Do you think about deaths you have been present at after your shift has ended?
- o How do you feel when you recall the experience ?
- o Can you describe your feelings when you recall such an experience ?
- o Do you do anything to make the experience of remembering better for you?
- o If you have positive or negative thoughts around a death can you explain why you feel differently about them ?

Appendix 6 Field Note Recording

Edinburgh Napier
UNIVERSITY

Participant Code

Interview Date / Start Time / End
Time

Pre-Interview Goals

Location of Interview

People Present

Description of Environment

Nonverbal behaviour

Content of interview

Research impressions (discomfort
of participants , emotional
responses)

Analysis (researchers questions ,
hunches, trends in data)

Technological problems

Appendix 7 Debrief sheet

"It's not our grief to have" – How palliative care nurses make meaning of loss and death when delivering end of life care

Thank you for participating in this research. I hope you have enjoyed the experience but if you feel you have any concerns regarding the issues discussed I have noted the contact details of the Chaplaincy Centre and the Occupational Health Department below.

The two departments are aware of the research project and understand that there may be participants of the study who require assistance. Please note that your involvement in the study is anonymous and all data is securely stored on a password protected laptop.

The results of the study will be presented once completed through an informal presentation to those wishing to attend and details of times and dates will be communicated to you in advance. The results may be published in academic journals.

Yours sincerely

Gerry Finnan

Contact details:

Chaplaincy Centre

Members of the Spiritual Care Team (Chaplains) are available to offer confidential, non-judgemental support to patients, relatives and staff, appropriate to their life-situation and beliefs. They are available to listen, to pray or simply to wait with people according to their needs and will arrange and facilitate referrals to the accredited representatives of any Church, Faith Community or other organisation as requested by any member of the hospital community.

Borders General Hospital

Melrose

Roxburghshire

TD6 9DA

01896 826564

Occupational Health

Borders Occupational Health Service provides support to all NHS Borders staff. Occupational health services are independent of both management and employees and are therefore able to give unbiased advice to both groups to the benefit of all. The service is also confidential.

Our aim is to improve the health, safety & general well-being of all employees ensuring a healthier & safer working environment.

Occupational Health Manager,

West End House,

High Street,

Melrose,

TD6 9RU,

ohsadmin@borders.scot.nhs.uk

01896 825982

Appendix 8 Example of annotation of the transcript

File Name(s)	12190_Nurse_3_interview
Total Recording Length	30 minutes
Number of Participants	2
Final Word Count	4,535
Total Number of Pages	10
Date Completed	06 May 2016

① needing a 'rest' from AC

② Short but sometimes 'severe' grief. + then move on.

③ pressure - not being able to spend time with patients family

④ communicate - knowing whats ahead anticipatory grief

I: Uhm-hmm. And do you feel that palliative care is where you'd like to continue? Would you prefer palliative care nursing to another type of nursing or are you quite open...?

R: Yeah. No, I prefer the palliative care to any of the other nursing that I've done. I still quite enjoy the stroke nursing and I think I'm quite lucky at nights that you'll rotate like that. You get a wee break every now and then.

I: Mm. Do you think that's important?

R: Uhm-hmm. Definitely. You can go months without getting a...but to go along for a few sets...a few shifts, just does make a difference. I'm quite lucky in the fact that the staff I work with tend to go along and help along at the stroke end at times anyway, because we have to help each other out. But it's quite good to actually get away for a complete break just every...just to recharge the batteries.

I: So just going back to you were talking about palliative care and you prefer to work in palliative care, why is that, do you think? What makes you...what draws you to palliative care then rather than another type of nursing? Can you explain anything around your thoughts and feelings on that?

R: I think it's just...to empathise with others and just to make a difference to them. I mean, I know in other nursing you can make a difference to continued life and all the rest of it, rehab and that sort of thing, but I just...there's just something about palliative care. You've got...you spend more quality time with the patients that you've got there and relatives. And it just makes...it makes a big difference. I just enjoy that side of the job. There are times when it can be frustrating when you're...somebody's in a lot of pain and you're [not getting on top of it 05:09] and that sort of thing, but...no, I just like that side of the nursing, just...

I: And then you talked about it's important to have a break to go on to the stroke side, for example, now and again. And why do you think it's important to have a break? What makes you...?

R: Sometimes it can just get...it can be quite...you get quite intense spells where there is a lot of grief and there's a lot of sadness and there's a lot...you've had a few deaths or there's been bad deaths and that and...you get the support from your colleagues and that round about you. But you're not really getting away from it as such. Whereas if you get a break at the other end, you can recharge your batteries. It's a different kind of nursing and it lets you concentrate on something else and gives that side of...probably that side of your brain a rest.

I: Mm. And is there any other support available to you as a nurse working in the palliative care unit? Or do you feel there's anything else that...?

3

pg 7

You do take some of it on yourself - not much choice in the matter.

self aware but can not help self feeling

- I think we (clinician) still grieve
- Do feel sorrow .
- Diffrent because you come in next day + concentrating on the rest that are there
- Probably sheltered away
- Similar situation reminds you of a patient you lost previously

delibrate answer. acknowledge grief . — moving on to next patient ? Still in background? recalling past patients .

- Not like the families grief going on and on — ours is very short

Can not be compared to families .

- Short burs: sometimes severe grief

— high in intensity

- Compartmentalized + move on to the next (patient) . pg7

statement of how it is.

<u>Aft death of a patient</u>

- It's nothing that you do RP
- go in + anothe patient needs you
- Focus on next patient - but not deliberatily switching off - somebody else <u>needs</u> you + that is your priority

*— normalize
— move on.
— new patient need g*

Appendix 9 Example of mind map process to map the themes
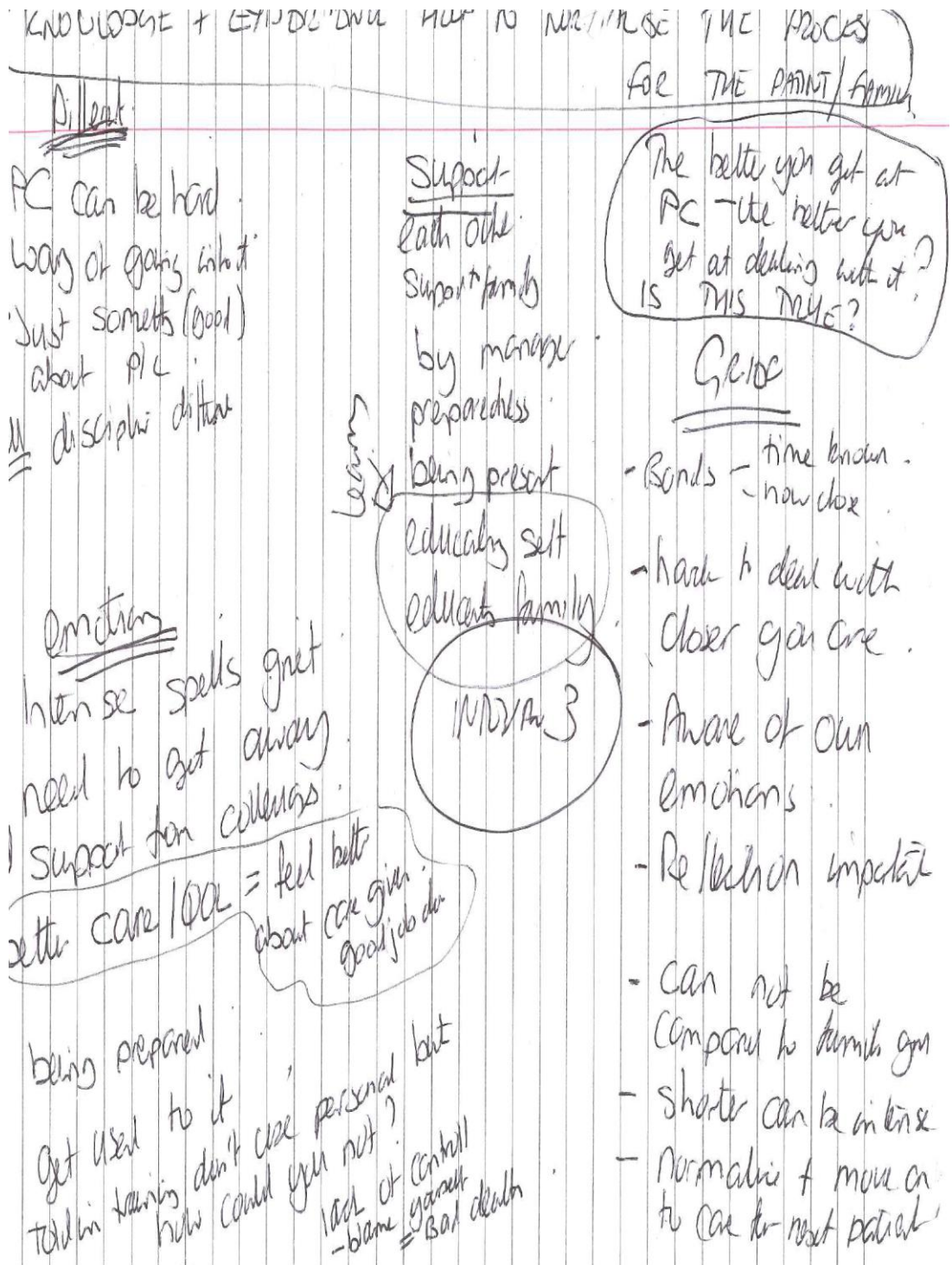
Appendix 10 Process to identify patterns from the analysis carried out to refine the themes

INT 3

Sub theme   theme

3

1. Good to get a break from PC — 2. *working full time*
2. Break needed so not too emotionally drained.
3. Can spend more time with the patient. — *being*
4. Making a difference. — *altruism inherent value*
5. Support from colleagues. — *good job*
6. It is important to be prepared. — *being*
7. Important that relatives know you are there.
8. Conflict of being "professional" and developing relationships with patients and families. — *profession V personal*
9. Being there for them. — *being*
10. Relief when patient dies. — *relief*
11. Can't help taking some feelings – experiencing grief. — *profess V person*
12. Short burst of grief – move on to next patient. — *move on*
13. Not a conscious decision to shelve grief but the next patient needing care becomes the purpose.
14. Scottish Borders small community – know patients and families. — *Borders*
15. The more experience of dying patients the better you become at dealing with it. — *experience*

accomodate of
profession & personal
expectations +
experiens

Just
Being

Job well
done altruism
include supp
hr fmmg
etc

death
anxiety
Transference

Web in
Borders

Reflection
impact.

Appendix 11 Example of Nvivo analysis

NVIVO Analysis

Original doc	Refs Per doc	Nodes Per doc	Identified Nodes across all docs	Collated intermediate themes across all docs	Final Superordinate Themes
Nurse_1	32	14	• Being	• Showing respect to the family and knowing when you are needed.	1. The importance of being.
Nurse_2	37	10	• Death anxiety		
Nurse_3	30	10	• Good job		
Nurse 4	52	10	• Grief	• You are a person not just a nurse.	2. The altruistic self.
Nurse_5	36	14	• Identify with patients and family		
Nurse_6	47	12	• How do you cope	• Just being there	
Nurse_7	52	14	• Inherent values	• Inherent Values and a job well done.	3. Separating the personal and the professional self.
			• Knowledge		
			• Letting go	• Support.	
			• Values and beliefs	• Being prepared.	
			• Reflection	• Relief after the death of a patient	
			• Relationships		4. Death anxiety and transference.
			• separate job and home	• Relationships and connectedness	
			• Support for patient and family	• Teamwork and training	
			• Team work	• Permission to grieve	
			• Transference	• Moving on	
			• Association with situation	• Too young to die	
			• Young age	• Standing in the shoes of the bereaved	
				• It could be me - I don't want to die. Resilience.	

Example of quotes from individual interviews which contributed to intermediate themes using Nvivo

Original document	Individual references
12188 _nurse_1	• Support patient and family = it's my job • Try to fight showing emotion • Find young death very difficult • Sad, they didn't have children • Felt part of the family
12189 _nurse_2	• Team work • Being prepared • Reflection • "putting yourself in their shoes" if they have children
12190_Nurse_3	• Needing a "rest" from PC now and again is important • Short but sometimes "severe" grief experienced by nurses • Pressure = not being able to spend time with the patient or family • Communication very important = knowing what's ahead and anticipatory grief
12191 _nurse_4	• Support for family – giving them a cuddle • Just being there for them • Feeling prepared and a job well done • Our job to normalise grief/death
12192_Nurse_5_	• Fear of being alone at point of death • Not having any family close by • Personal reasons -losing a close family member
12193__Nurse_6_	• Support for family important • Difficult if you know patient beforehand • Young age with young children • Not feeling good enough at job " have I done everything I could "
12194_ _nurse__7	• Losing a child • Grief/sadness goes so far then you have to stop it • Am I normal to feel like this? • I am professional – don't show grief/emotion